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## **Ethnic differences in caregiving processes in first-episode psychosis**

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# Ethnic differences in caregiving processes in first-episode psychosis

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**Submitted by Lindsay Smith**

in partial fulfilment of the requirements of the Degree of  
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Institute of Psychiatry, King's College London

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## **Background**

Few studies have investigated the impact of caregiving on a national scale, or ethnic differences in caregiving processes. This is despite growing numbers of informal carers and demographic change in the UK. Individuals identifying as black African, black Caribbean, black British and black 'other' (BA\_BAC) by UK Census ethnicity criteria (2001) are currently over-represented within psychiatric services in urban settings and are known to perceive statutory support to be inappropriate for their needs.

## **Aim**

Initially, to examine the mental and physical health consequences of caregiving in general. Secondly, the aim was to compare ethnic differences in the processes identified within cognitive models of caregiving in psychosis. The third aim was to assess the validity of a new measure of service users' perceptions of the quality of caregiving relationships.

## **Method**

Primary outcome measures obtained from the Adult Psychiatric Morbidity Survey (APMS) 2007 were used to examine the physical and mental health impact of caregiving roles compared to no caregiving in a representative sample of households in England. In the second study, BA\_BAC carers and carers who identified as white British or white 'other' (WB) were recruited through Early Intervention in psychosis services in London. The Camberwell Family Interview was used to assess Expressed Emotion and computerised self-report measurements were obtained of distress, appraisals of caregiving, explanatory models of illness and coping. Within and between groups comparisons were conducted cross-sectionally based on self-identified ethnicity. In the third study, a systematic review was conducted to identify items to measure perceived Expressed Emotion. An aggregated scale was completed by first-episode psychosis service-users who agreed to accompany their carers in participating in the studies, along with a clinical interview assessing symptoms.

## **Results**

25% (N=1883) of the APMS 2007 sample identified themselves as carers in study 1. They had poorer mental health, and higher psychiatric symptom scores than non-caregivers. A significant dose effect was found, with an observable decline in mental health above 10 hours per week. A twofold increase in psychiatric symptom scores in the clinical range was recorded in those providing care for more than 20 hours per week. In adjusted analyses, there was no excess of physical disorders in carers. In the first-episode psychosis sample (study 2), over one third of all carers (N=78) exceeded clinical thresholds of depressive symptoms. Sixty-five percent reported sleep problems and poor sleep was found to mediate

the relationship between negative appraisals of caregiving and distress ( $p<.0001$ ). BA\_BAC carers ( $N=41$ ) were less likely to report intrusive, overprotective behaviours in caregiving and they maintained higher levels of warmth in discussing their relative. Significant group differences were recorded in carers' beliefs about the causes of illness and their coping strategies. In study 3, a measure of service-user perceived Expressed Emotion showed moderate to good reliability and validity, taking into account illness severity. Better performance was observed for the measure with BA\_BAC service-user participants ( $N=12/44$ ).

### **Conclusions**

Even at low levels of caregiving, (10 hours a week) there is observable impact on the mental health of carers. This is found from the initial stages of caring for someone with a mental health condition. Distress frequently reaches clinical thresholds, particularly for individuals providing the most care, and those trying to cope with complex needs. Strategies aimed at maintaining carers' mental health must consider this adverse and often progressive impact. Ethnic group differences in responses to caregiving may affect reported well being in carers and their interactions with service users. This is relevant to the development of culturally-informed Family Interventions in psychosis and interventions aimed specifically at carers. Measurement instruments targeting service-user perceptions of caregiving relationships may have clinical applications, particularly for ethnically diverse groups.

### **STATEMENT OF ORIGINALITY**

The studies in this thesis are partly based on an evaluation of a body of work by Professor Elizabeth Kuipers in the area of caregiving research in psychosis. The author devised studies 1-3. The hypotheses and most of the measures for study 2 were developed with the advice of, and in collaboration with, Dr Juliana Onwumere. Professor Paul Bebbington at University College London provided additional guidance in the development of study 1. Unless otherwise stated in the thesis, all work, including recruitment, interviewing, ratings, data processing and analyses, is the authors own.

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

(Signed)\_\_\_\_\_

## **ACKNOWLEDGEMENTS**

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My clinical sponsors and each of the care co-ordinators in the 10 London-based Early Intervention services were a great support in facilitating contact with participants, at a time when resources were especially sparse and case-loads were large.

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In this thesis WB denotes any individual who identified as white British, Scottish, English, Irish or white ‘other’ at the time of assessment, according to UK Census (2001) ethnicity criteria.

BA\_BAC denotes any individual who identified as black African, black Caribbean, black African-Caribbean or black British of African or Caribbean descent at the time of assessment.

The heterogeneity of these groupings is acknowledged and limitations associated with ethnic group categorisations are discussed within.

The following acronyms are used with regularity within the thesis:

EE	Expressed Emotion
CFI	Camberwell Family Interview
EOI	Emotional Overinvolvement
CC	Critical Comments
PC	Perceived Criticism

The abbreviations below are used in analytic tables for studies 2 and 3:

ECI_neg	ECI negative appraisals of caregiving: (mean aggregate score, 10 subscales)
ECI_pos	ECI positive appraisals of caregiving: (mean aggregate score, 2 subscales)
BIPQ_conseq	BIPQ beliefs about consequences of illness, mean score (1 item)
BIPQ_control	BIPQ beliefs about control of symptoms, mean score (1 item)
BIPQ_timeline	BIPQ beliefs about duration of illness item, mean score (1 item)
COPE_avoid	B-COPE Avoidant coping, sum mean score (8 items)
COPE_religious	B-COPE Religious coping, sum mean score (2 items)
COPE_positive	B-COPE Positive coping, sum mean score (8 items)
CES_D	CES-D total mean score
BAI	BAI total mean score
SF_36_PCS	SF-36 physical component summary score
SF_36_MCS	SF-36 mental component summary score
PSQI	Pittsburgh Sleep Quality Index, overall mean score
FAS_tot	Family Attitude Scale, mean total score

Brief COPE subscales (mean aggregate score, all subscales 2 items):

C_ACT	Active coping subscale
C_PLA	Planning coping subscale
C_POS	Positive-reframing coping subscale
C_SUB	Substance-use coping subscale
C_DEN	Denial coping subscale
C_BDIS	Behavioural disengagement coping subscale
C_MDIS	Mental disengagement coping subscale
C_REL	Religious coping subscale
C_ACP	Acceptance coping subscale

Experience of Caregiving Inventory (ECI) subscales; carers’ appraisals of:

ECI_DEPEND	Service user dependency
ECI_LOSS	Feelings of loss
ECI_DIFFBEH	Difficult behaviours
ECI_FAMILY	The effect the illness has had on the family
ECI_SERVICE	Difficulties with services
ECI_STIGMA	Stigma
ECI_NEGSYM	Negative symptoms
ECI_GOOD	The good aspects of the relationship
ECI_POSIT	Rewarding personal experiences from caregiving

## **Chapter 1: Carers: an introduction**

### **1.1 Caregiving terminology**

Around the world, large numbers of people provide help and support to friends or relatives unable to manage independently as a result of ill health or old age (*Shahly et al., 2012*). This remains a normative, often rewarding, and yet potentially stressful function of daily life (*Brody, 1985*), regardless of culture and the role and responsibilities of the individual in a society (*Willis, 2012*). Historically, the study of supportive personal relationships was the reserve of sociologists and anthropologists (*Zarit, 2006*). However, in the last several decades, an increase in community care led approaches by public health systems (*Kakuma et al., 2011*), combined with growing concerns over provisions to meet the needs of an aging population (*Christensen et al., 2009*), has contributed to diversified and intensified research interests in caregiving relationships, and in particular in what is now commonly referred to as ‘informal’, ‘family’ or ‘unpaid’ care.

These terms were introduced to the discourse to distinguish additional caregiving activities, associated with longer-term disability, illness or aging, from ‘normal’ familial obligations and reciprocities (*Glendinning et al., 2009*). Naturally, variations in the definition of ‘informal’ care, influenced by diverging societal attitudes to familial roles and availability of formal health care provision, have led to difficulties in generating reliable estimates of the frequency of informal caregivers and making comparisons across countries (*Colombo et al., 2011*). Different operational terminology for informal caregiving have included for example specification of care-recipient characteristics, assistance with particular activities of daily living, duration of caregiving or time spent caregiving on a weekly basis.

Regardless of the terminology however, a common aim has been to identify a threshold beyond which caregiving responsibilities may have a detrimental effect on an individual’s health and social and economic security. Understanding the circumstances that are associated with, or enable the prediction of, poorer outcomes for carers is a legitimate public

policy concern for health systems that support carers themselves, and the individuals who rely upon them to fulfil as autonomous a life as possible.

## 1.2 Quantifying caregiving populations

The most recent UK Census 2011 estimates that one in ten people in England and Wales are currently involved in such caring (*Office for National Statistics, 2012*). This is equivalent to the proportion recorded ten years ago, when questions on unpaid care were first introduced to the Census, but it represents an increase in the actual numbers of carers given the rise in the general population. Attempts to quantify the caregiving population nationally began in 1985 as part of the General Household Survey series (*Maher & Green, 2002*) and a number of survey series since then have generated national estimates (**Table 1**). Variations in survey design and methodology make direct comparisons across studies difficult, except for the UK Census, for which updated and more detailed analyses of the caregiving population aged 16 and over in England are due for publication (*White, 2013*).

**Table 1: Age-standardised frequency of informal carers aged 16 and over, England**

Percentage of respondents	Any amount of care	≥20 hours a week
Census 2011	-	-
Survey of Carers in Households 2009/10	10.9	5.2
General Household Survey 2000 Carers Module	16.1	4.1
Census 2001	12.3	3.9
Family Resources Survey (2004/05)	11.1	3.6
Family Resources Survey (2005/06)	11.8	3.6
British Household Panel Survey (2007)	17.0	3.5

Amended from Department of Health (2010) Survey of Carers in Households 2009/10, p. 156

In general, women are more likely than men to be carers, to report longer durations of caregiving and higher amounts of caregiving on a weekly basis (*Department for Health, Survey of Carers in Households, SCH, 2010*). The same is true of older people and those with lower household incomes (SCH). Detailed analyses from Census data (2001) have also revealed more complex relationships, for example that men above the age of 65 are

statistically more likely to provide care than women of the same age group (*Del Bono et al., 2009*). This was explained in terms of the greater likelihood of older men to be married than older women. The need to adopt an age-standardised approach to the study of caregiving relationships is also recommended for individual ethnic group comparisons, where mean ages are typically lower than the national white British majority. Individuals from Bangladeshi, Pakistani and Indian backgrounds have been shown to be more likely than white British individuals to provide informal care, though the frequency of caregiving was comparable amongst other ethnic minorities (*Sproston & Nazroo, 2002*). The relative contributions that cultural versus socioeconomic factors make in explaining ethnic variations in propensity to provide informal care are debated in research (*Hirst, 2000*).

### **1.3 Caregiving theory**

Identifying and taxonomising positive experiences from caregiving and integrating these into existing theory has been a focus of recent research (*Zarit, 2012; Kate et al., 2012; Carbonneau et al., 2010*). Beneficial psychological effects, for example personal growth and enhanced interpersonal relationships (*Onwumere et al., 2008; Chen & Greenberg, 2004*), as well as physical effects, including greater activity (*Fredman et al., 2008*), have been highlighted to counterbalance perceived preoccupation with the negative impact of caregiving (*Veltman et al., 2002*).

For many years, defining the negative concept of ‘carer burden’ (*Carretero et al., 2009*) and developing measures for it (*Van Durme et al., 2012; Reine et al., 2003; Schene et al., 1994*) dominated investigations into caregiving. Much of this work was led by those examining the effects of psychiatric patients returning home after inpatient stays (*Zarit, 2006; Brown & Rutter, 1966*). Interest in the family environment of individuals with severe mental health conditions was piqued following the mass closure of asylums in the UK in the 1970s and the reintegration of inpatients into community placements (*Killaspy, 2006*). In one of the first attempts to provide a fully formed definition, Platt (1985, p.383) described burden as ‘the

*presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patients' significant other(s), e.g. members of the household and/or their family'.*

Although not explicit in this instance, the notion that the patient, and caring for them, is a direct cause of negative effects for the carer is central to early definitions (*e.g Platt, 1985; Grad & Sainsbury, 1963*).

Further developments in the concept included identification of different domains (*Schene et al., 1998*) or dimensions of burden (*Schene, 1990*) for example health, financial or emotional. In addition, a distinction was drawn between objective and subjective dimensions of burden (*Hoenig & Hamilton, 1966*). The former refers to effects that can be observed externally, for example loss of employment, the latter incorporates a subjective evaluation of the impact of care and is more closely aligned with the idea of distress. This distinction provided a way to interpret why in highly stressful situations certain carers still reported lower rates of burden. It also paved the way for models of caregiving which place emphasis on the role of cognitive appraisals (*e.g Kuipers et al., 2010*).

Despite continual revisions to the definition of 'carer burden', limitations led researchers to propose more comprehensive frameworks within which to conceptualise a broader concept of caregiving or 'impact of care' (*Szmukler et al., 1996*). These limitations included, that carer burden does not incorporate positive dimensions of caring, that it implies passivity on behalf of the carer and that it lacks consideration of social context (*Kuipers & Bebbington, 2005*). Instead, 'impact of care' is a concept that is based on models of stress and coping (*Lazarus, 1966*). It is now common to consider caregiving as a dynamic process of adapting to stress within which internal appraisals of events and coping play a critical role in moderating the impact of care at various time points in the trajectory of caregiving (*Lazarus & Folkman, 1984*).

The application of stress theory within medicine and the cognitive sciences was developing in parallel with the growth in scientific enquiry into caregiving relationships (*Zarit, 2006*).

Within this more detailed model individual differences and current resources play a large part in determining existing vulnerabilities to stress. Stressful external circumstances associated with caring are thought to trigger internal reactions, including negative emotions and negative thinking or appraisals of caregiving (*Lazarus & Folkman, 1984*). These reactions may in turn be associated with less effective or short-term coping strategies including avoidance or loss of touch with social supports, thus predicting the subsequent impact of caregiving across multiple dimensions (*Pearlin et al., 1990*). Pathways to subjective burden or psychological distress are inherent to the model. As for physical impairment, in addition to the ‘wear and tear’ associated with physically challenging caregiving activities, this may result either directly from the bodily impact of stress hormones (for example in diminishing immune function) or indirectly via poorer diet, increased smoking, consumption of alcohol and other substance abuse as responses to stress (*Vitaliano et al., 2003*). Positive responses to caregiving are also explainable within the model via affective, cognitive and behavioural pathways.

#### **1.4 The health of carers**

Research on the health consequences of caregiving has largely established that caregivers have poorer psychological and physical health outcomes than non-caregivers, although many people report few, if any, negative effects (*Schulz & Sherwood, 2008*). Carer burden, measured either by scores on a scale of subjective feelings or by the number of hours spent in caregiving has been associated with the magnitude of this difference (*Buyck et al., 2011; Phillips et al., 2009*). However, there are a limited number of studies that have been designed to examine whether there is an independent effect of caregiving on health (*Legg et al., 2013; Hirst, 2005*).

Meta-analyses have reported a consistent association between caregiving and poorer mental health outcomes for caregivers (*Pinquart et al., 2003*). Individual studies have investigated the role that vulnerabilities and resources play in moderating this relationship, with social

support and sleep problems for example being implicated in the process (*Shah et al., 2010; Phillips et al., 2009; Schulz & Sherwood, 2008*). Effect sizes for physical health have however been smaller, and fluctuate between improved or impaired physical health in comparison to non-caregivers (*Vitaliano et al., 2003*). These findings have been attributed in part to methodological issues including variation in sample sizes, care-recipient characteristics, outcome measurements and control of confounding factors (*Pinquart & Sörensen, 2007*).

The majority of studies investigating mental health in caregivers have employed self-report measures of psychiatric symptoms, focussing on depression and anxiety, however, fewer have included clinical assessments allowing diagnostic categorisation (*Kapari et al., 2010; Schulz et al., 1995*). Amongst reviews of those studies which do, caring (for individuals with dementia) has also been associated with elevated risks for clinical levels of anxiety and depression, compared with matched samples of non-caregivers (*Cooper et al., 2007; Cuijpers, 2005*).

However, the first national survey of common mental disorders in caregivers over the age of 16 in England reported no significant differences overall between caregivers and non-caregivers in the number of people reaching clinical thresholds for neurotic symptoms within age-standardised comparisons (*Singleton et al., 2002*). This was assessed by lay interviewers using the Clinical Interview Schedule – Revised (CIS-R) (*Lewis et al., 1992*). Certain subsamples of individuals were however more vulnerable to elevated levels of psychiatric disturbance, for example, female carers reported higher CIS-R scores than both men and women in the general population. In addition, caring for spouses, and caring for younger people remained associated with increased likelihood of clinically significant total scores on the schedule ( $>12$ ), even after adjustment (*Singleton et al., 2002*). Of particular note within the present context, individuals looking after someone with mental as well as physical difficulties were twice as likely to reach CIS-R clinical thresholds as those looking after relatives with physical problems alone. This is consistent with studies suggesting that



carers looking after those with mental as well as physical health complaints experience higher levels of carer burden (*Hastrup et al., 2011*). The sample size did not permit ethnic group comparisons in the survey. However, comparisons made in an earlier population-based study of psychiatric illness in ethnic minority carers reported few significant differences in CIS-R scores among carers across ethnic groups, although there was some statistically significant variation by ethnicity in scores on summary physical health variables (*Weich et al., 2004*).

### **1.5 Valuing carers: a UK government policy perspective**

With these potential health consequences for carers in mind, in the UK, a Carers Strategy has prioritised the early identification of individuals with caring responsibilities so that they can be supported to maintain their physical and mental health (*Department of Health, 2008*). General Practitioners have been targeted as a critical first point of contact in encouraging individuals to identify themselves as carers at an early stage (*Cormac & Tihanyi, 2006*), while ‘quick tools’ to assess level of care provision and its impact for the individual are in development (*Cameron et al., 2011*). For those providing regular and substantial care, for example to someone with mental health problems supported under the Care Programme Approach, a carers’ assessment to review their own needs should be provided (*Kingdon, 1994*). Yet recent studies have suggested that administration and uptake of carer assessments may only be reaching one quarter of carers eligible and that this is related to reports of reduced continuity of patient care (*Burns et al., 2012*). Concerns also remain about ensuring equality of access to services, for example across socioeconomic (*Lamura et al., 2008*) and ethnic groups (*Cooper et al., 2013*). Evidence suggests that caregiving does not always result in increased use of services (*McCrone et al., 2005*).

Further priorities within the current Carers Strategy update (2010), ‘*Recognised, valued and supported: next steps for a carers strategy*’ include enabling people to fulfil their educational, employment and other social ambitions in addition to their caregiving role.

Revisions to UK carer policies since the initial 1995 Carers Act have borne out increasing awareness of the diversity of carers needs and would appear to depart from the notion of carers simply as a ‘resource’ in the care of others to be valued for their ability to offset formal healthcare costs (*Twigg & Atkin, 1994*), by acknowledging the fundamental human rights of carers themselves, for example to engage in work freely, under European Law (*Council for Europe, European Convention on Human Rights, 1950*). A high amount of informal caring is associated with reduced probability of employment (*Colombo et al., 2011; Carmichael et al., 2010*).

Yet the financial and social significance of informal carers is substantial and attempts have been made to value the contribution carers make in terms of cost savings to the national economy, albeit with significant methodological challenges (*Koopmanschap et al., 2008*). These include how to factor in the potential health cost associated with caring (*Van den Berg et al., 2004*) and its impact on labour force participation (*Bevan et al., 2013; Viitanen, 2007*).

From a policy perspective, strategies to help carers maintain their health are set against the backdrop of the UK government’s ambitious new public health plan (*Health and Social Care Act, 2012*) that stipulates ‘*No health without mental health*’, that acknowledges the growing contribution of mental disorders to the global burden of disease (*Prince et al., 2007*) and the inextricable links between physical and mental health (*Naylor et al., 2012*).

## **Chapter 2: Psychosis: an introduction**

Schizophrenia and related psychoses, as diagnosed, presently rank third in terms of global societal costs associated with mental ill health (*Collins et al., 2011*). Notwithstanding the overwhelming personal impact, in the UK alone psychosis is estimated to cost £11.8 billion per year in care and loss of productivity, with the public sector contributing £7.2 billion. Families contribute not just in terms of private expenditure to meet care needs but also often in loss of employment (*Andrew et al., 2012; Mangalore & Knapp, 2007; Knapp et al., 2004*). Identifying culturally appropriate, cost effective preventions and interventions is therefore a worldwide research priority (*Collins et al., 2011*).

### **2.1 Clinical concept and theory**

Although ‘case’ descriptions with reference to psychotic phenomena have existed for centuries, ‘Schizophrenia’ emerged as a clinical term in psychiatry in the late 19<sup>th</sup> and early 20<sup>th</sup> centuries to describe a severe form of psychosis as distinct from manic depression (*Tandon et al., 2009; Wing, 1992*). Today its conceptualisation remains under scrutiny and revision in light of advancing knowledge about its causes and mechanisms (*Freeman et al., 2012*). Fortright arguments have also been made that a symptom-based approach may be more appropriate from a therapeutic point of view (*Bentall, 2003*). Use of the name even in clinical practice is being renounced in favour of alternatives that may be less socially stigmatising, for example psychosis, or more conceptually informative e.g aberrant salience syndrome (*Silveira et al., 2012; Van Os, 2009; Kingdon et al., 2008*).

Nevertheless, psychotic conditions are diagnosed categorically within current international classification systems (on the basis of symptom patterns, their severity and duration) with the purpose of facilitating predictions about course and outcome, and to guide treatments (*Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-V), American Psychiatric Association, 2013; International Classification of Diseases-10 (ICD-10), World Health Organisation (WHO), 1992*). Reality distortions remain hallmark symptoms. These include

delusions or false beliefs (held with varying degrees of certainty, on the basis of a poverty of information or despite evidence to the contrary) as well as hallucinations, typically auditory (Peters, 2001; Jaspers, 1997). Delusions held with conviction and hallucinations have been referred to over time as ‘positive symptoms’ of psychosis, in acknowledgement of their additive effect to ‘normal’ experience (Andreasen & Olsen, 1982), and as ‘first rank’ symptoms, in attempts to identify symptoms specific to schizophrenia (Nordgaard et al., 2008; Schneider, 1959). However, whilst these can be sufficient for a diagnosis of a psychotic disorder (depending on presentation, duration and exclusion of alternative diagnoses) they are not necessary (Dutta et al., 2007). Characteristic psychotic symptoms are observable across a range of organic and non-organic conditions (Lautenschlager & Förstl, 2001) and are reported at attenuated levels within the general population (Ian et al., 2010; Nuevo et al., 2010; Van Os et al., 2009; Johns & Van Os, 2001).

Despite ongoing debate about the reliability and validity of current classifications (Tandon, 2012; Kapur, 2011), schizophrenia has been diagnosed across countries with standardised instruments (Jablensky et al., 1992) and is estimated in the crudest global terms to affect 7 people in every 1000 in their lifetime (McGrath et al., 2008). It was one of the first psychiatric conditions to be studied globally and as a result of influential WHO studies (*International Pilot Study of Schizophrenia*, Sartorius et al., 1972; *Determinants of the Outcome of Severe Mental Disorders*, Jablensky et al., 1992) was considered a universally occurring, although now differentially expressed, syndrome (Jablensky & Sartorius, 1988). Reported differences in form, course and outcome across cultures are considered to hold promise in understanding more about the condition (Stompe & Friedman, 2007).

Symptoms of psychosis are typically first expressed by individuals in adolescence and early adulthood, with the age of onset, at least in western countries, being marginally lower in males (Eranti et al., 2013; Venkatesh et al., 2008; Jablensky & Cole, 1997). This can be, but is not always, preceded by a period of unsettling changes in memory, concentration or cognition, the emergence of bizarre thinking, feelings or behaviour, and difficulties with

communication and social functioning (*Schultze-Lutter, 2009; Yung & McGorry, 1996*). Identification and examination of individuals who seek help for these so-called ‘prodromal’ signs of psychosis is a priority for prevention work (*Addington & Heinssen, 2012*). However, the development of criteria to predict those at greatest risk remains a challenge (*Van Os & Murray, 2013; Salokangas & McGlashan, 2008*). Recent European estimates suggest that, over 18 months, less than a fifth of people indicated ‘At Risk’ will go on to develop psychotic symptoms reaching clinical thresholds (*Ruhrmann et al., 2010*). Considerable variation also exists in this estimated rate of ‘transition to psychosis’ across studies (*Fusar-Poli et al., 2013; Correll et al., 2010*)

For individuals who do go on to experience a ‘first-episode’ of psychosis, which is marked by the expression of frank psychotic symptoms (*McGorry et al., 2006*), the pattern and course of illness is highly variable (*Tandon et al., 2009*). Approximately one fifth are estimated to experience a full psychopathological remission (*Jääskeläinen et al., 2012; Lang et al., 2012*). Criteria are continually debated for assessing clinical and functional recovery (*Andreasen, 2006*). The remaining majority are predicted to experience a further episode within 3 years, with individual patterns of recovery, symptom exacerbation or recurrence over their lifetime and some continued disability (*Clemmensen et al., 2012; Haro et al., 2008*). In the longer term, one in two people can expect to regain sustained periods of reasonable social functioning, at a level un-envisaged prior to modern treatments (*Harrow et al., 2005; Menezes et al., 2006*). Evidence suggests that those who receive pharmacological treatment earlier have a better prognosis over the shorter term (*Leucht et al., 2012*). However, it is acknowledged that whilst drug treatment may dampen the distressing effect of positive symptoms, it deals neither with the content nor the cognitive mechanisms that give rise to them (*Kapur, 2003*). Any lapse in medication can cause symptoms to return and there are concerns that the experience of symptoms following medication may be qualitatively more acute as a result of brain sensitisation (*Kapur, 2003*). Psychosocial interventions are therefore recommended in combination with medication (*Van der Gaag et al., 2011; Bird et*

*al.*, 2010; Pharoah *et al.*, 2010; National Institute for Clinical Excellence (NICE) *Guideline for Schizophrenia (update)*, 2009). These have been shown to increase the likelihood of preventing relapse by at least two fold by comparison to drug treatment alone (Alvarez-Jimenez *et al.*, 2011a).

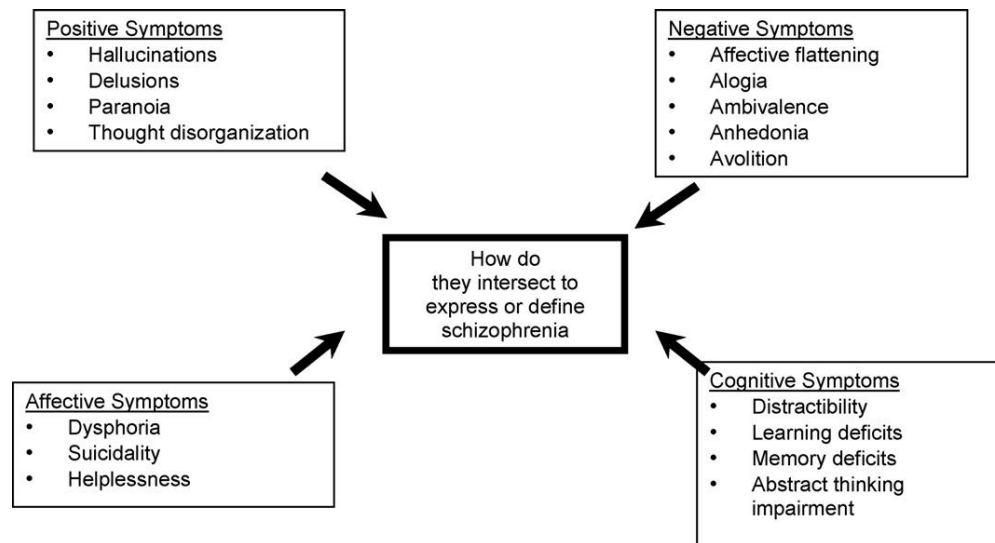
The current classification systems remain structurally rooted in the theoretical work of German psychiatrist Emil Kraepelin (1919). He drew a distinction between ‘*Dementia Praecox*’ (later, although not synonymously, described as schizophrenia by Eugen Bleuler (1911/1951) with its early presentation and deteriorating course, and ‘*Manic Depressive Psychosis*’ with its principle affective dimensions and episodic course (Ashok *et al.*, 2012). This formulation was made on the basis of observed phenomenology and outcomes and was rooted in a medical model which aimed to identify disease entities or illnesses (Fischer & Carpenter, 2009). This diagnostic dichotomy remains within current systems but is under review in light of, amongst other things, neurobiological evidence suggesting some shared genetic and brain structural risk profiles between schizophrenia and bipolar disorder (manic depression) (De Peri *et al.*, 2012; Craddock & Owen, 2010).

The latter part of the 20<sup>th</sup> Century saw a number of clinicians and theorists attempt to contend with the incredibly diverse clinical presentations of ‘schizophrenia’ by refining operational criteria (Dutta *et al.*, 2007). Subtypes were identified to distinguish between for example ‘*Paranoid Schizophrenia*’, which gives prominence to fearful delusions and ‘*Catatonic Schizophrenia*’ which is identifiable by a lack of motor or behavioural mobility or unresponsiveness (McGlashan & Fenton, 1991). This deconstructed the idea of schizophrenia as a singular illness and reconceived of it as a syndrome with divergent manifestations with pathologic commonalities (Van Os & Tamminga, 2007). Today, these subtypes have recently been deleted from the revised *Diagnostic and Statistical Manual of Mental Disorders* (5<sup>th</sup> ed., DSM-V, American Psychiatric Association, 2013) due to their inefficacy in differentiating in the expected course or treatment for disorder. A consensus is emerging in favour of conceptualising schizophrenia in terms of domains of pathology

(Carpenter, 2007) or symptom dimensions (Van Os *et al.*, 1999; Costello, 1992), as well as illness course or stages (Owen *et al.*, 2011; Tandon *et al.*, 2008). Kraepelin did latterly go on to acknowledge the benefits of a hierarchical-dimensional model of schizophrenia (Jablensky, 2010). Furthermore, his eponymous dichotomy is overemphasised to the extent that he later acknowledged the potential co-existence of *Dementia Praecox* and *Manic Depression* (Jablensky, 2010). A later ‘intermediate’ subtype, referred to as ‘*Schizoaffective Disorder*’, was included within the classification systems to account for this but its clinical utility is also currently being reviewed (Cheniaux *et al.*, 2008).

Example domains or dimensions being proposed for consideration in the revision of classification systems are illustrated in **Figure 1, overleaf**. Specific standardised instruments to assess difficulties in each of these areas have been proposed and are in development (Tandon *et al.*, 2006). Furthermore, it is an issue of ongoing debate whether or not to conceive of these domains as pathological, and symptoms expressed within them as qualitatively distinct from ‘normal’ experience, or as continua that extend fully into the general population (Peters, 2001). Recent evidence from meta-analytic studies conducted across countries have suggested that between 4% and 9% of healthy individuals experienced ‘psychosis-like’ symptoms; this has challenged the former view (Nuevo *et al.*, 2010; Van Os *et al.*, 2009). Models now exist which allow both for the distribution of symptom dimensions within the normal population and for qualitatively different pathological processes that contribute to the development of illness (Johns & Van Os, 2001; Claridge & Beech, 1995). The primacy and differential expression of symptoms in each of the dimensions may vary during the illness course (Peralta & Cuesta, 2001).

The case for a dimensional approach to the illness has been strongly influenced by reports of cross-cultural differences in the clinical presentations of schizophrenia (Stompe *et al.*, 2006a) and of the content and form for example of delusions and hallucinations experienced by individuals (Bauer *et al.*, 2011; Yamada *et al.*, 2006). It is hoped that this may lead to greater diagnostic and prognostic specificity (Vega & Lewis-Fernández, 2008).

**Figure 1:** Example domains of psychopathology in psychosis

Tandon &amp; Maj, (2008); p. 25

Higher rates of both auditory and visual hallucinations have for example been recorded in non European ethnicities admitted to hospital in London (Ndeti & Vadher, 1984), as well as in the community (Johns *et al.*, 2002). In cross-country comparisons religious delusions and delusional guilt have been more frequently observed in Christian by comparison to Muslim communities (Stompe *et al.*, 2006b). These are general associations which would benefit from further explanation of which specific aspects of culture or religiosity influence symptom expression (Gearing *et al.*, 2011), particularly in light of non-replicability across studies (Van der Ven *et al.*, 2012). However, it is well-established that an individual's immediate cultural environment influences cognitive appraisals and the derivation of meaning in psychosis (Cottam *et al.*, 2011; Bhavsar & Bhugra, 2008). Hence, it is argued that culture and ethnicity should cease to be viewed as confounding variables in approaches to studying psychosis but rather as '*fundamental elements driving its expression and interpretation*' (Dutta *et al.*, 2007; p. 873).



## 2.2 Epidemiology

Variation in prevalence and incidence rates of psychosis is an area of research that has been extensively explored from a cross-cultural perspective. Beginning with Kraepelin's reports of dementia praecox and manic depression in Javanese communities in the early 20<sup>th</sup> century, past epidemiological studies have however received criticism for their inconsistencies and therefore incomparability (*Jablensky, 2007*). The World Health Organisation's International Pilot Study in Schizophrenia (*IPSS, WHO 1973; Sartorius et al., 1986; Sartorius et al., 1972*) addressed these concerns for the first time by adopting a standardised methodology to examine prevalence of schizophrenia across nine countries beginning in the late 1960s. Two broad conclusions were drawn from the IPSS (*Harrison et al., 2001; Leff et al., 1992; Sartorius et al., 1977*) and its follow-up incidence studies: the Determinants of Outcomes of Severe Mental Disorders (*Jablensky et al., 1992*) and the Assessment and Reduction of Psychiatric Disability (*Wiersma et al., 1996*). The first was that the incidence levels of schizophrenia were roughly comparable across countries, leading to the aforementioned assumption about the universality of the illness (*Jablensky & Sartorius, 1988*). The second was that individuals in developing countries (India and Nigeria at 2 and 5 year follow-up) had a more positive prognosis (*Hopper et al. 2007*).

The accuracy of both of these conclusions has since been called into question (*Esan et al., 2012; Cohen et al., 2008; McGrath, 2006; Edgerton & Cohen, 1994*). The original architects of the WHO studies have responded by claiming that although these conclusions may be frequently-cited, they are oversimplifications of the data presented (*Jablensky & Sartorius, 2008*). Even using the narrowest diagnostic criteria for schizophrenia, the IPSS studies reported at least a two-fold variation (7 to 14 per 100,000) in incidence rates across sites (*McGrath et al., 2006*). The researchers argued that as far as prognosis is concerned, to continue to debate a binary and uniform 'developed' versus 'developing' nations distinction, is to undermine the more complex and interesting point that social and cultural factors appear to modify outcomes (*Jablensky & Sartorius, 2008; Harrison et al., 2001*). For

example, in response to Cohen and colleagues' (2008) criticisms of the WHO conclusions, Leff (2008) points to regional differences in ratings on an empirical measure of family interactions and the family climate (Expressed Emotion) across the WHO sites, and the power of these ratings in predicting clinical outcomes (*Kuipers et al., 1992*).

Since these defining WHO studies a sizeable and increasingly rigorous body of evidence has amassed indicating that informative variations in incidence rates do exist across countries, within localities and also across social and ethnic groups (*McGrath et al., 2008; McGrath et al., 2004*). A consistent finding has been that of higher incidence rates of psychosis in ethnic minorities internationally, with a mean weighted relative risk ratio of developing schizophrenia amongst migrants and their offspring of 2.9 by comparison to the baseline population (*Fearon & Morgan, 2006; Cantor-Graae & Selten, 2005*). In the UK, at least 16 studies have provided relative risk ratios (RRs) of developing schizophrenia and other psychoses (*Kirkbride et al., 2012*). These report RRs of between 2 and 16 for ethnic minorities by comparison to white or white British groups (*e.g Coid et al., 2008; Fearon et al., 2006; Kirkbride et al., 2006; Morgan et al., 2006a*). A recent systematic review and meta-analysis of incidence of schizophrenia and other psychoses in England, 1950 –2009, has surmised and confirmed individual reports that those presently at highest risk of developing illness are black people of Caribbean (pooled RR: 5.6; 95% CI: 1.3-4.5) or African origin (pooled RR: 4.7; 95% CI: 3.3-6.8; N=5); (*Kirkbride et al., 2012*). Studies on South Asian individuals have been fewer but still show elevated rates of psychotic disorder by comparison to the white (British) population (pooled RR: 2.4; 95% CI:1.3-4.5; N=3) (*Kirkbride et al., 2012*). A number of studies additionally document urban-rural differences in incidence rates of psychosis, with a recent meta-analysis reporting a two-fold increase in incidence rate ratios in the most urban locality of a region versus the most rural locality of a region (*Vassos et al., 2012*).

These differences in incidence rates are of interest when considering the aetiology of schizophrenia spectrum disorders. Although schizophrenia is known as a strongly heritable

condition that arises as a result of a complex interaction of biological, psychological and social factors (*Tandon et al., 2008*), studies conducted amongst native Caribbean populations in Jamaica, Trinidad and Barbados for example (*Mahy et al., 1999; Bhugra et al., 1996; Hickling & Rodgers-Johnson, 1995*) show reduced or no excess incidence compared to global rates (estimated to be 15.2 per 100,000 in *McGrath et al., 2004*). Taken together these results have been interpreted as suggesting a strong contribution of environmental factors, at least to certain clinical manifestations of disorder. These are interesting targets for clinicians and health workers because they can potentially be changed.

However, alternative explanations for the variation in incidence levels have been proposed, including selective migration and misdiagnosis. It was originally hypothesised that raised rates of illness amongst migrants may be because those vulnerable to schizophrenia are predisposed to migrate (*Selten et al., 2002*). Yet, this neither explains the marked difference in incidence rates across different migrant communities (*Pinto et al., 2008*) nor the observation of raised incidence rates amongst second generation black Caribbeans and black Africans (*Bourque et al., 2011*). Those studies that have addressed the issue of misdiagnosis suggest that whilst diagnostic reliability amongst practitioners from different ethnic backgrounds may be questionable (*Hickling et al., 1999*) differences do not occur in a systematic fashion that would explain over-diagnosis in ethnic minorities (*Selten & Hoek, 2008; Sharpley et al., 2001*).

The contribution that different environmental or social factors play in conferring risk for the development of disorder have therefore been examined at an *individual level* (e.g social deprivation, unemployment, substance misuse), at a *community level* (urbanicity, isolation, ethnic density) and at a *societal level* (perceived discrimination, stigma, social capital) (*Kirkbride & Jones, 2011*). A complementary research strand investigates how immediate social support systems and positive social interactions at a *familial level* may help in the management of and recovery from illness, particularly during early stages (*Addington et al., 2003; Kuipers et al., 2002*).

For example, at an *individual level* both psychosis-like experiences in healthy populations and first-episode psychosis case status have been associated with measures of childhood and adult social disadvantage including parental separation and family breakdown (*Morgan et al., 2007; Morgan & Fisher, 2007*), unemployment and poverty (*Morgan et al., 2009; Morgan et al., 2008*). Reports suggest that higher rates of unemployment and lower socio-economic status may characterise immigrant communities (*Hjern et al. 2004; Rutter et al., 1975*). Theorists have speculated as to whether socioeconomic adversity is a cause of schizophrenia (the environmental ‘breeder’ hypothesis) or whether individuals who are vulnerable to schizophrenia are more likely to find themselves in socially adverse environments (the downward-drift hypothesis) (*Cooper, 2005a*). Demonstration of dose-response associations between socio-economic indicators and illness outcomes within controlled studies (*Srireddy et al. 2012*) as well as interaction effects (*Van Os et al., 2003*) provide support for at least a bi-directional relationship. However, to date evidence seeking to explore additive effects between ethnicity and markers of social disadvantage remains equivocal (*Srireddy et al., 2012; Boydell et al., 2012; Kirkbride et al., 2008a; Reininghaus et al., 2008*). The search therefore continues for an explanatory model that incorporates risk associated with both social class and migrant status in a way that explains first, psychosis specific observations (white people from lower socioeconomic groups and immigrants in the UK for example do not appear to show comparably large differences in incidence for other forms of mental disorder) and second the apparent importance of the time in life during which these effects are experienced (*Cooper, 2005b*). To this end a sociodevelopmental pathway to illness has recently been proposed (*Morgan et al., 2010*).

At a *community level*, other studies have explored the opposing concepts of ‘social capital’ and ‘social isolation’ by examining incidence levels of psychosis in relation to degrees of, or amount of, ethnic density. Evidence suggests that neighbourhoods which are socially disorganised, that lack cohesion and a shared sense of community may be more susceptible to mental illness than poor communities (*Shaw et al., 2012*). For example ethnic minorities

living in predominantly white neighbourhoods have been found to have a higher incidence of psychosis than those in which people in their local area are mostly from their own ethnic group (*Kirkbride et al., 2008b, Veling et al., 2008b; Boydell et al., 2001*). It is hypothesised therefore that there may be a ‘protective’ effect of living in a geographically and culturally ‘close-knit’ community and it has been suggested that South Asians living in the UK may not be as geographically dispersed or socially isolated as black Africans and Caribbeans (*Bhugra et al., 1997*). This has been considered as a possible contributing factor to variation in incidence rates of psychosis across migrant communities of different ethnicities. Both social support and discrimination (experienced and perceived) have been examined as possible mechanisms to explain the relationship between ethnic density and mental health (*Das-Munshi et al., 2010*). For example, incidence of psychosis has been observed to rise in association with level of reported discrimination (*Veling et al., 2008a, 2007; Janssen et al., 2003*). There is also evidence that perceptions of disadvantage may explain associations between strong ethnic identification and increased rates of psychosis in black ethnic minority groups (*Reininghaus et al., 2010; Veling et al., 2010; Cooper et al., 2008*).

This emerging consensus about ethnic differences in the incidence rates of psychosis internationally, and specifically within the UK of elevated rates in black Caribbeans and Africans and their children, reaffirms the application of psychosocial theories in psychosis by highlighting possible pathways not just to illness but also to prevention (*Kirkbride & Jones, 2011; Morgan & Hutchinson, 2010; McGrath & Susser, 2009*). Advanced statistical modelling has been used to speculate on the impact that removal of attributable risk associated with socioeconomic factors of ethnic minorities would have on psychosis rates. Data suggest that 22% of all new cases of psychosis illness in the UK may potentially be preventable, representing 67% of cases within minority groups (*Kirkbride et al., 2010*). However, it is unclear how this would be achieved.

## **2.3 Aetiology**

### **Gene-environment interactions**

From an aetiological point of view the means by which environmental or social factors may 'cause' dysfunction have been considered more specifically, and within the context of an undisputed and substantial genetic contribution to illness liability, estimated at approximately 80% (*Cardno & Gottesman, 2000*). A compilation of all family and twin studies conducted over seventy years across Europe (1920-1987) indicated that risk of schizophrenia increases in proportion to amount of shared genes (*Gottesman, 1991*). First-degree relatives of someone with schizophrenia, who have 50% shared genes (children, siblings) have risk ratios for illness that are approximately double those observed in second degree relatives who share 25% of their genes (nieces/nephews). Furthermore, for one in every two monozygotic twin-pairs, in which one individual has the disorder, both individuals present with the illness. By contrast for dizygotic twins, in which only 50% of genes are shared as opposed to 100%, the likelihood of developing illness if your twin is affected drops to approximately one in six (*Gottesman, 1991*). Yet rather than preclude the contribution of environmental factors in illness course, genetic studies also provide support for their influence (*Tsuang, 2000*). Risk does not precisely correlate with genetic profile, if it did co-occurrence of illness would be expected in all cases of monozygotic twins whose genetic sequence is identical. Moreover, no single gene has been identified that confers a large effect on risk (*Allen et al., 2008*). Rather, the aetiology of schizophrenia and related psychoses and the diverse domains of dysfunction observed therein are hypothesised to arise from an aggregation of multiple small-effect genetic abnormalities, biological and social environmental factors (*Tsuang et al., 2001*).

Theoretically there are at least three ways to conceptualise the influence of environmental factors in the aetiology of illness (*Van Os & McGuffin, 2003*). These need not be mutually exclusive given the different clinical presentations of psychosis to be explained (*Ellman & Cannon, 2008*). First, environmental factors may have a direct pathogenic effect, this is

consistent with the hypothesis that two forms of psychosis exist, one that is genetic and the other caused by the environment (*Van Os & McGuffin, 2003*). Evidence for the hypothesis is minimal. However, it has been proposed that certain cases of schizophrenia arise from a viral infection in adulthood (*Torrey et al., 2007*). Second, a genetic diathesis may be necessary although not sufficient for the development of disorder, with vulnerability and pathology arising in a synergistic fashion from the *interaction* of environmental factors and genetic effects (GXE), or their *addition* (G+E) (*Mittal et al., 2008; Van Os et al., 2008*), and third, genes may be the only necessary cause of dysfunction. Environmental and social factors may precipitate episodes, or relapse, modify symptom expression and course of illness (for example by covariation, rGE) but not in a fashion that would be considered truly causal (*Van Os & McGuffin, 2003*).

However, with a number of environmental risk factors identified, with larger effects on risk than any genetic abnormality (*Maki et al., 2005*), and with neurobiological pathways proposed via which these might operate (*Van Winkel et al., 2008*), the second of these options, the diathesis-stress model, has received most research attention (*Nuechterlein & Dawson, 1984*). In addition to migration, an increased risk of schizophrenia of approximately two-fold has been associated with urban upbringing (*Pedersen & Mortensen, 2006*), season of birth (*Davies et al., 2003*), maternal infections and malnutrition in early pregnancy (*Penner & Brown, 2007*), obstetric and perinatal complications (*Byrne et al., 2007*) as well as cannabis use in adolescence (*Ruiz-Veguilla et al., 2013; Murray et al., 2007; Henquet et al., 2005; Semple et al., 2005*) and adverse life events (*Varese et al., 2012; Read et al., 2009; Khashan et al., 2008*). Delineating the possible interactions these factors may have with genetic variations is complicated by the vast number of gene allele and copy number variants that have been associated with schizophrenia, frequently without replication or an idea of their role in protein synthesis (*Tandon et al., 2008*). Nevertheless, examples of putative gene-environment interactions in humans are supported by indirect and direct analyses. For example, urbanicity has been shown to predict different outcomes in psychosis

in those with and without a familial liability for illness (*Van Os et al., 2003*). In addition, an allelic variation in the catechol-O-methyltransferase gene involved in dopamine synthesis has been reported to have a moderating effect on stress-induced psychotic symptoms (*Stefanis et al., 2007*). Modelling of gene-environment interactions is therefore presently considered critical in advancing our understanding of psychosis aetiology (*Leboyer et al., 2008*).

### **The dopamine hypothesis, dysregulation of the hypothalamic pituitary axis and a role for psychosocial stressors**

At a neurobiological level subcortical dopamine dysregulation resulting in an excess of dopamine in the striatal areas of the brain is identified as the principal mechanism for the development of ‘positive’ psychotic symptoms (*Van Winkel et al., 2008*). There is greater debate however as to the pathways resulting in clinical features in other dimensions (e.g. cognitive and negative; *Howes & Kapur, 2009*). The development of the dopamine hypothesis began with the discovery of the efficacy of first-generation antipsychotics in reducing psychotic symptoms by blocking dopamine receptors in the brain. More recently the hypothesis is supported by Positron Emission Tomography scanning studies of acutely psychotic patients (*Howes et al., 2011; 2009*). Tracking radiolabelled dopamine substrates as a proxy for levels of dopamine in the brain, studies have consistently documented elevated presynaptic striatal dopamine levels in psychosis patients by comparison to controls (*Howes & Kapur, 2009*).

In terms of evidence supporting an influence of environmental risk factors on dopamine dysregulation, low levels of self-reported maternal care for example have been associated with increased striatal dopamine release in reaction to social stress by comparison to high maternal care (*Pruessner et al., 2004*). In addition, dopaminergic over-activity has been reported in animal experiments designed to model social isolation or defeat and subordination, as associated with ethnic minority status (*Morgan et al., 2002; Tidey & Miczek, 1996*).



Dysregulation in the hypothalamic pituitary axis (HPA) which controls hormone secretion in response to stress (*Biondi & Picardi, 1999*) is an auxiliary neurobiological pathway that has been identified as a potential mediator of the effect of environmental risk factors on psychotic symptom induction (*Myin-Germeys & Van Os, 2007*). Evidence of HPA functional abnormalities in patients are reported (*Bradley & Dinan, 2010*), including for example increased cortisol and adrenocorticotrophic hormone levels in drug naïve patients (*Ryan et al., 2003*) and elevated cortisol release in response to pharmacologic challenge (*Walker et al., 2008; Elman et al., 1998*) by comparison to controls.

Environmental risk factors implicated in the aetiology of disorder, including prenatal maternal stress (*Glover, 2011; Kofman, 2002*), adverse life events (*Beards et al., 2013*) and in particular childhood abuse have been associated with altered HPA function (*MacMillan et al., 2009; Tarullo & Gunnar, 2006*). A model based on behavioural sensitisation to stressful stimuli has therefore been proposed, in which cumulative impact of stressful events leads to increased sensitivity to HPA dysregulation (*Van Winkel et al., 2008, Walker et al., 2008*). Evidence is growing as to how at a neurobiological level this interacts with the dopamine neurotransmitter system with some initial findings supporting a link between HPA-controlled hormone secretion and increased levels of dopamine in certain brain regions (*Czyrak et al., 2003; Moghaddam, 2002*).

In addition to a role for a *cumulative* effect of stressful environmental events on HPA function there has also been a role hypothesised for a *differential* effect of types of psychosocial stressor in psychosis. Theoretical work by Dickerson and Kemeny (2004) identified two key features of events which produced maximal cortisol reactions in humans in a meta-analysis of 208 studies: judgement by others and uncontrollability. In a follow-up to this work Jones and Fernyhough (2007) propose that stressors perceived as ‘socially-evaluative’ and uncontrollable may be of particular significance in the aetiology of psychotic symptoms. This is consistent with the hypothesis of a principal role for the experience of social defeat or ‘outsider’ status in the development of psychotic symptoms (*Selten &*

*Cantor-Graae, 2007*) and is based on a human instinct to preserve a theoretical ‘social self’ by maintenance of self-esteem and status (*Jones & Fernyhough, 2007*). Direct empirical evidence to support this hypothesis is difficult to achieve given the ethical considerations associated with involving patients in potentially stressful socially-evaluative events (*Selten & Cantor-Graae, 2005*). However, significant cortisol activation may be generated in individuals by subjecting them to circumstances in which they are ignored or ostracised (*Stroud et al., 2000*). In addition, intrusive and threatening life events have been associated with psychosis onset (*Raune et al., 2009*), and general adverse life events with symptom exacerbation in first onset groups (*Ventura et al., 2000*).

With the aim of bridging the explanatory gap between hyperdomanergia in the striatal areas of the brain and the more complex clinical expression of positive symptomatology in psychosis, Kapur and colleagues have postulated a role for ‘aberrant salience’ (*Kapur et al., 2005; 2003*). Subcortical dopamine neurotransmitter systems are implicated in reward processing and signalling of the salience, importance or relevance, of an internal or external event or stimulus (*Berridge, 2007; Schultz, 2002*). Delusions and hallucinations are thus hypothesised to be the result of an individual’s attempt to make sense of the erroneous signals being received from a dysfunctional ‘salience system’. Howes and Kapur (2009; p. 555) surmise that ‘*psychosis is, therefore, aberrant salience driven by dopamine and filtered through the individual’s existing cognitive and sociocultural schemas – thus allowing the same chemical (dopamine) to have different clinical manifestations in different cultures and different individuals.*’ It is this ‘filtering’ or ‘appraisal’ of experiences of aberrant salience that is central to cognitive explanations of the emergence and persistence of psychotic symptoms and their associated distress and impairment (*Garety et al., 2007*).

## 2.4 Cognitive model of positive symptoms in psychosis

### Cognitive, emotional and social mechanisms

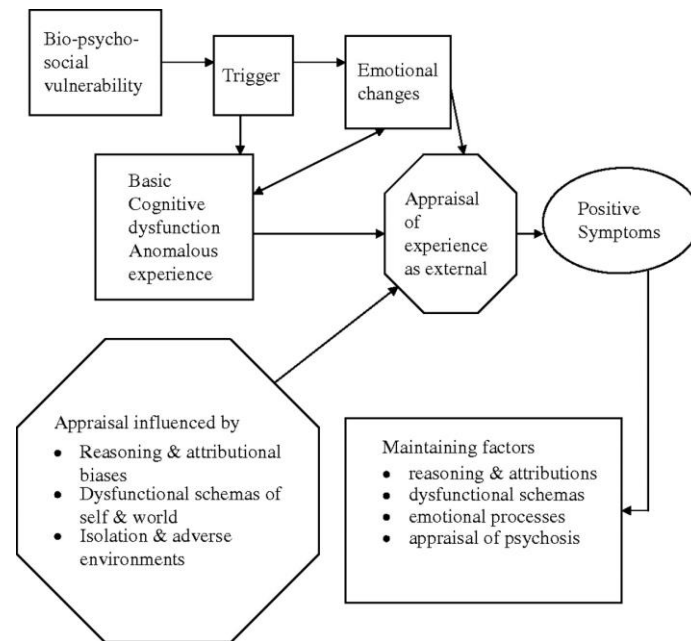
Building on previous cognitive approaches in psychosis (*Maher, 1999; Hemsley, 1998; Frith, 1992; Morrison et al., 1995; Bentall et al., 1994; Chadwick & Birchwood, 1994*). Garety et al.'s (2001) model of the emergence and maintenance of positive psychotic symptoms (**Figure 2, p. 35**) places strong emphasis on the pathognomic nature of a particular type of appraisal of anomalous experiences. It is the evaluation of a bizarre mental event associated with striatal dopamine dysfunction or aberrant salience as '*external to the individual*' and '*personally significant*' that is proposed to be critical in initiating a '*cascade of increasingly deviant development*' (*Bramon & Murray, 2001; p. 243*).

Evidence supporting the existence of psychotic-like symptoms in the normal population, or of a psychosis-continuum (*Kaymaz et al., 2012; Van Os et al., 2009*), is integrated into the model in that the experience of a psychotic symptom occurs in the normal population and does not itself constitute the 'beginning' of the development of psychosis (*Gaudiano & Zimmerman, 2013*). This is critically hinged on a maladaptive appraisal of the event and associated distress (*Kuipers et al., 2006a; Garety et al., 2001*). Negative affect and negative affective reactions to common symptoms of psychosis are acknowledged as important in distinguishing clinical from non-clinical cases and in determining the level of impairment experienced by an individual (*Gumley, 2010; Birchwood, 2003*). Hallucinations and delusional ideation held with conviction, are for example reported amongst evangelical and new religious groups without the accompanying levels of distress as those observed in psychotic patients (*Davies et al., 2001; Peters et al., 1999*).

The model assumes that vulnerability to psychosis is synergistically determined by biological, psychological and social risk factors (*Borrell-Carrió et al., 2004; Engel, 1977*). It implicitly allows for neurodevelopmental and sociodevelopmental pathways giving rise to a predisposition to experience psychotic events and to interpret them as externally-created and threatening (*Kuipers et al. 2006a, Garety et al. 2001*). It is distinctive however from other

accounts in its specification of cognitive, emotional and social mechanisms that elicit psychotic symptoms and play a role in their persistence.

**Figure 2: Cognitive model of the positive symptoms in psychosis**



*Kuipers et al., (2006a); p.S25; as discussed in Garety et al., (2001)*

### Psychosocial vulnerability

As far as predisposition to disorder is concerned there is a significant body of evidence that links early childhood trauma (*Clarke et al., 2013; Larsson et al., 2013; Varese et al., 2012; Arseneault et al., 2011*), victimisation (*Kelleher et al., 2008*), and in particular sexual abuse (*Thompson et al., 2013; Bebbington et al., 2011*) with increased risk for psychosis and with psychotic symptoms in non-clinical groups. Certain studies additionally suggest that particular types of abuse may predict the form or content of symptoms (*Bentall et al., 2012; Hardy et al., 2005*). Bentall et al. (2012) for example report specific associations between childhood rape and hallucinations, and between being brought up in institutional care and paranoia. Furthermore they note a dose-response relationship between number of childhood traumatic incidents and risk of symptoms. The mechanisms continue to be debated by which childhood trauma may cause psychosis (*Bendall et al., 2013*). With both negative affect (*Freeman & Fowler, 2009*) and negative cognitions (*Gracie et al., 2007*), for example low

self esteem and extreme beliefs about the self and others, being implicated in the development of processing deficits and cognitive intrusions that may be appraised as symptoms of psychosis (Kuipers *et al.* 2006a; Morrison, 2001).

In addition to their contribution to affective and cognitive biases associated with vulnerability to psychosis, adverse life events are also conceived within the model as triggers for anomalous experiences (Kuipers *et al.* 2006a). Clustering of life events prior to an episode of psychosis is observed (Raune *et al.* 2009; Bebbington *et al.*, 1996) and there is evidence suggesting they play a role in conversion to psychosis within ‘at risk’ groups (Tessner *et al.*, 2011; Bechdolf *et al.*, 2010). Horan *et al.* (2005) found that individual appraisal of the controllability of these life events was as important as frequency in dictating resultant distress in patient groups.

### **Emotional changes**

Whilst a qualitative distinction between psychosis and the neuroses still theoretically underpins current classification systems (Häfner *et al.*, 2005; Freeman & Garety, 2003) it is now well-documented that emotional disturbances exist prior to the onset of a psychotic episode, during an episode and following (Hartley *et al.*, 2013; Romm *et al.*, 2010). Depression in psychosis for example has been associated with self-harm, suicidal ideation (Challis *et al.*, 2013; Palmier-Claus *et al.*, 2013) and increased rates of relapse and hospitalisation (Scholes & Martin, 2013). In addition to distress, evidence suggests that mood may influence the onset and severity of psychotic symptoms; their content and persistence (Hartley *et al.*, 2013; Ben-Zeev *et al.*, 2012; Freeman, 2007; Green *et al.*, 2006; Krabbendam & Van Os, 2005; Krabbendam *et al.*, 2005; Birchwood, 2003). For example, anxiety has been associated with perceptions of threat within the context of developing paranoia (Freeman, 2007). Worry has been associated with perceived implausibility of persecutory delusions (Freeman *et al.*, 2012). Furthermore, using experience sampling technology, fluctuations in negative affect have been associated with real-time changes in

levels of paranoia (*Myin-Germeys et al., 2005*). Stress reactivity and depressive symptoms are reported as mediating this relationship (*Kramer et al., 2013*).

### **Cognitive mechanisms**

In terms of cognitive mechanisms, greater insight has been associated with increased levels of depression in psychosis (*Cotton et al., 2012; Mintz et al., 2003*). However, it is also associated with better treatment adherence (*Buckley et al., 2007*) and outcome (*Drake et al., 2004*). Negative schematic beliefs and low self-esteem are thought to influence appraisals of core cognitive disturbance and have been associated with delusions and hallucinations in cross-sectional studies (*Fowler et al., 2006; Smith et al., 2006*), and with changes in paranoia in longitudinal studies (*Erickson & Lysaker, 2012*). Recently a role for negative cognitions in mediating the relationship between mood and psychotic symptoms has also been implied from structural components modelling (*Fowler et al., 2012*). In addition, safety seeking behaviours have been shown to relate specifically to maintenance of beliefs about the omnipotence of voices (*Hacker et al., 2008; Nothard et al., 2008*) and to delusional persistence (*Freeman et al., 2007*). This has been explained in terms of the role of experiential avoidance in preventing the acquisition of disconfirmatory evidence in evaluating experiences (*Garety et al., 2001*). There is also further support for the role of safety behaviours in mediating the relationship between threat appraisals and anomaly-related distress (*Gaynor et al., 2013*).

Individuals who go on to develop persistent psychotic symptoms can also exhibit biases in their reasoning processes, the attributions they make about events and deficits in theory of mind (*Langdon et al., 2010; Penn et al., 2008; Garety et al., 2005*). For example, a significant body of evidence documents the existence of a ‘jumping to conclusions’ (JTC) reasoning bias in patients (*Startup et al., 2008; Freeman et al., 2008; Fine et al., 2007; Garety & Freeman, 1999*). This is considered a bias in data gathering which leads to decisions being made on the basis of a poverty of evidence and is consistently reported across clinical trials in patients with delusions by comparison to controls (*Freeman, 2007*).

Studies suggest that extreme levels of JTC may be specific to individuals with delusions in psychosis (*Lincoln et al., 2010; Peters et al., 2008*) and may predict delusional conviction (*Freeman et al., 2008, Garety et al., 2005*). As a result research has focused on conceptualising JTC reasoning processes, determining its causes and its relationship to the development of different types of delusions (*Freeman et al., 2007*). In support of a dimensional model, JTC biases have been reported in At Risk groups (*Broome et al., 2007*) and in the general population (*Moritz et al., 2012; Freeman et al., 2008*). There is additional evidence to suggest that tendency toward JTC bias may be associated with both psychosis liability and present level of delusional ideation; thus suggesting it may be both a state and a trait factor (*Freeman et al., 2007; Dael et al., 2006*). Belief inflexibility was shown in one study to mediate the relationship between JTC and conviction in delusions (*Garety et al., 2005*). JTC is associated with an inability to generate alternative explanations for experiences (*Freeman et al., 2004*) and with deficits in integrating disconfirmatory evidence into decision making (*Woodward et al., 2008*). This may be an extension of a normal confirmational bias (*Freeman et al., 2002*). In a single study of 301 psychosis patients recruited as part of the Psychological Prevention of Relapse in Psychosis Trial (*PRP*), Garety and colleagues (2012) also demonstrated that JTC reasoning may play a greater role in the development of grandiose delusions specifically, by contrast to persecutory delusions.

In addition to JTC reasoning biases, a number of smaller clinical-control comparisons suggest a greater tendency amongst psychosis patients to attribute blame for negative events to external factors, particularly to other people (*Sharp et al., 1997; Fear et al., 1996; Lyon et al., 1994*). This has not been replicated in all studies and caution has been advised in interpreting findings as evidence of a direct empirical relationship between externalising attributional style and persecutory delusions (*Freeman, 2007*). Further studies would need to control for a reported association between attributional bias, depression and grandiosity (*Jolley et al., 2006*). Nevertheless, a recent study by Rowland et al., (2013) compared 126 participants with a diagnosis of schizophrenia, 97 individuals with bipolar and 81 controls

and confirmed an externalising attributional bias amongst the schizophrenia group. They postulated a role for its development in the regulation of negative affect.

### **Social environment**

These identified processes interact within the context of a protective or conducive social environment (*Garety et al., 2001*). Perceived social support has been shown to reduce significantly vulnerability to subsequent episodes of psychosis (*Alvarez-Jimenez et al., 2011b*), to reduce hospitalisations (*Norman et al., 2005*), to decrease negative symptoms and to improve overall functioning (*Tempier et al., 2012; Uzenoff et al., 2010*). By contrast declining social support prior to a first-episode has been shown to predict negative symptoms and duration of untreated illness (*Devyllder & Gearing, 2013*). Consistent with this, individuals living in highly critical or emotionally intrusive family environments are significantly more likely to relapse than those with warm, supportive family relationships (*Butzlaff & Hooley, 1998; Bebbington & Kuipers, 1994*). In addition to the provision of alternative explanations for experiences and disconfirmatory evidence in belief formation, it is hypothesised that supportive caregiving relationships may elicit a protective effect on the cognitive processes of individuals with psychosis, by reducing environmental stress and improving affect (*Garety et al., 2001*).



## **Chapter 3: Caregiving in psychosis**

### **3.1 Literature review methodology**

#### **Structure**

The conceptual breadth and heterogeneity in design of studies investigating caregiving processes in psychosis, and across ethnic or cultural groups, necessitated a mixed-methods approach to reviewing the literature (*Dixon-Woods et al., 2005*). Systematic review methodologies (*Moher et al., 2009*) were employed along with narrative (*Baumeister and Leary, 1997*) and thematic (*Dixon-Woods et al., 2005*) synthesis techniques in an iterative process. Firstly, the review was divided into three broad categories or topic areas a) studies investigating caregiving processes in psychosis specifically b) experimental approaches to the measurement of cultural differences in psychology and c) studies investigating caregiving processes in psychosis from a cultural perspective. The review was structured in this way to enable the identification of a general theory or model of caregiving in psychosis within which ethnic specific studies could be interpreted.

A preliminary search of the literature was conducted to identify existing reviews of caregiving in psychosis which had conceptual development as their principal goal. A cognitive model of caregiving (*Kuipers et al., 2010*) was identified as the framework within which to organise and structure further literature searches. This was selected because the model was borne out of a recent synthesis of empirical findings obtained specifically in psychosis groups, and because of its direct intended application to the design of therapeutic interventions.

A second introductory research question was also addressed as part of this preliminary search: how does the experience of caregiving for individuals with psychosis differ qualitatively from caregiving for other people? No formal coding system was employed to synthesise this body of literature. However, a series of themes were identified from previous reviews and qualitative studies including for example a) age of onset of psychosis and its impact on carers' interpretation of symptoms b) contact with services and issues with

navigating service user confidentiality c) uniquely bizarre symptoms and idiosyncratic trajectories of illness d) high rates of violence and suicidality in service users with psychosis. This body of literature forms the next **Section, 3.2.**

The remainder of the literature searches were categorised into topics according to the key caregiving processes identified in the cognitive model of caregiving and shown in **Figure 3, Section 3.8.** These included a) impact of care/carer burden/cognitive and affective changes in carers b) appraisals of service user symptoms including attributions (explanations) made about service user' behaviours c) beliefs about mental illness/models of illness d) coping styles and e) Expressed Emotion, an empirical construct that measures what happens at the communication interface between carers and service users.

### **Search strategy**

The following databases were used for all searches: Embase; Medline and PsychINFO through OVIDSP and Pubmed. Previous reviews in each of the topics were identified to begin with and were used to prioritise within which areas a fully systematic review of the literature would make the greatest contribution. Given the centrality of the issues to the present study, systematic reviews were conducted to assess firstly cultural variability in the manifestation of Expressed Emotion and secondly the measurement of patient perceptions of Expressed Emotion and their validity as research and clinical constructs. Papers with "Expressed Emotion" AND "cultur\*" or "ethnic\*" in the title or keywords are discussed in **Section 4.6** and the synthesis of studies is presented in **Appendix 1.** The full details of the review conducted on Perceived Expressed Emotion are given in **Study 3, Chapter 8.**

Search strings for the remaining topic areas were created by conjoining variant descriptions of the relevant cognitive process in caregiving, with "cultur\*" or "ethnic\*". For example: "carer burden", "impact of care", "caregiving appraisals", "caregiving experience" AND "cultur\*" OR "ethnic\*". Quarterly updates were made during the study period to literature

lists collated within Zotero Bibliographic software manager 2.0.1, Center for History and New Media, George Mason University, Fairfax, VA, USA.

#### **Inclusion/Exclusion criteria**

The searches were limited to studies available in English and largely to those published in the last 25 years. Seminal papers published prior to this were included, as identified from existing reviews.

#### **Quality appraisal and literature synthesis**

Given the limited number of studies examining caregiving in psychosis from a cultural perspective the reviews conducted were designed to be as inclusive as possible. Quality assessment frameworks were not employed in selecting studies. However, priority was given in synthesising and discussing the literature to:

- studies employing similar validated methodologies or conceptual frameworks to the present research e.g the Camberwell Family Interview or the self-regulation model of illness beliefs (*Leventhal et al., 1984*)
- studies conducted within the ethnic populations in question
- studies conducted with migrant groups in the UK

Unless otherwise specified, the narrative sections of the literature review reflect the author's synthesis of findings, based on a non-coded thematic analysis.

### 3.2 Carers of individuals with psychosis

Carers of people with psychosis face unique challenges associated with this role that distinguish their experiences from other caregiving relationships. Individuals report the early stages of illness to be bewildering, frightening and frustrating, mainly for the afflicted person, but also for those around them (*McCann et al., 2011; Barker et al. 2001*). Carers regularly have to contend with bizarre or embarrassing behaviours (*Sin et al., 2005; Lauber et al., 2003*), extreme levels of self neglect (*Yung & McGorry, 1996*), and even threatening or aggressive behaviour as their relative tries to cope with the effects of the illness (*Hanzawa et al., 2013; Fazel et al., 2009; Dean et al., 2007; Swanson et al., 2006*). The typical age of onset of psychosis means that changes usually co-occur with adolescent development (*Mackrell & Lavender, 2004; Prymachuk., 1996*). This can obscure signs and symptoms of illness that may be clearly identifiable at other stages (*Jones, 2009; Askey et al., 2007*). Underlying problems may additionally be masked by recreational drug use or co-morbid substance abuse (*Carrà et al., 2012a; De Haan et al., 2004*) which are documented at elevated rates in first-episode groups by comparison to the general population (*Donoghue et al., 2011; Lambert et al., 2005; Van Mastrigt et al., 2004*). The extent to which these factors contribute to delays in seeking medical support can leave carers feeling guilty about not having ‘noticed sooner’ (*Tanskanen et al., 2011*). Yet family members play a critical role in navigating initial contact with services (*Fridgen et al., 2013*). Greater family involvement is associated with a shorter duration of untreated illness (*O’Callaghan et al., 2010; Anderson et al. 2010; Oliveira et al., 2010; Sharifi et al., 2009; Morgan et al., 2006b; Chen et al., 2005*).

If their relative is aged 18 or over then they are legally an adult and must self-present at National Health Services in order to receive medical support (*Davies, 1997*). This fact means that in practice it can be difficult for family members to negotiate on behalf of their relative who may be lacking insight into their condition or experiencing symptoms or feelings of stigma that may impede them from seeking help independently (*Morant et al., 2011*;

*Bergner et al., 2008; Drake et al. 2000*). As a result carers may find themselves in crisis situations involving emergency services (*Anderson et al., 2010*) and can be thrust into an unfamiliar sectioning process in which they play a role in their relative's compulsory admission to hospital (*Riley et al. 2011; Ridley et al., 2010*). There are particular concerns amongst service-users, families and mental health professionals alike about the standards of care provided by inpatient facilities (*The Abandoned Illness, UK Schizophrenia Commission Report 2012*).

Studies suggest that individuals from ethnic minority backgrounds are more likely to access medical support via the prison service and to have pathways to care that involve compulsory admission (*Ghali et al., 2012; Lawlor et al., 2012; Morgan et al., 2005a; Morgan et al., 2005b*). In the UK the majority of these studies have compared black African and Caribbean samples with white British samples (*Singh et al., 2007*). Multi-ethnic group comparisons are less common (*Bhui et al., 2003*). However, a relatively recent meta-analysis suggests that black patients in particular may be more likely to be detained than both Asian and white patients (*Singh et al., 2007*). Furthermore, detention rates for black Caribbeans have been related to perceptions of problems with services amongst their carers (*Boydell et al., 2013*). These differentials have been scrutinised to inform policies directed at ensuring equality of access to care (*Ascoli et al., 2012; Bhopal, 2012; McKenzie & Bhui, 2007*).

Other issues for ethnic minority carers may include questions over where and whether to seek help. Alternative explanations for illness may guide help-seeking behaviours and access of treatment (*Codjoe et al., 2013; Brown et al., 2011*). Ethnic minorities also report higher levels of distrust in medical services than white British groups (*Chakraborty et al., 2011; Mclean et al., 2003; Keating et al., 2002*). However, evidence is inconclusive as to whether these factors lead to an increase in the duration during which early signs and symptoms of disorder are untreated (*Ghali et al., 2012; Anderson et al., 2010; Broussard et al., 2010; Compton et al., 2009*). Within South London, in which incidence rates of psychosis are estimated to be the highest in the UK (*Kirkbride et al., 2012*), results from the Aetiology and

Ethnicity in Schizophrenia and other psychosis (AESOP) study suggests there are no differences in the duration of untreated illness across ethnic groups (*Morgan et al., 2006b*)

Once individuals do get in contact with services there are two central communication issues for carers which emerge from the literature. Firstly, a requirement for, and perceived lack of information (*Askey et al., 2009*) and secondly difficulties in responding to the impact that patient confidentiality has on their involvement (*Slade et al., 2007*). Family members who may for some years prior to contact with services have been supporting someone ‘round the clock’ and through distressing circumstances suddenly find themselves excluded from decisions about their relative’s care (*Jones, 2009*). In these difficult first stages of illness carers report feelings of anger, fear, resentment, guilt, loss and shame (*Gray et al., 2009*). For some, the illness may so severely affect their relative that the experience is akin to a bereavement that results in profound feelings of grief (*Patterson et al., 2005*). In addition to elevated rates of depression by comparison to the general population, carers of individuals with psychosis also report symptoms of trauma (*Kingston, 2013; Loughland et al., 2009; Barton & Jackson, 2008*). All this is compounded by the experience of stigma associated with mental health issues, particularly schizophrenia (*Henderson & Thornicroft, 2009; Thornicroft et al., 2009*). It has been suggested that this stigma may be more acutely felt by those within ethnic minority communities already confronting prejudice or discrimination associated with their ethnic group affiliation (*Gary, 2005*). Furthermore, feelings of shame and guilt have been implicated as prominent dimensions of stigma in ethnic minorities (*Knifton et al., 2010; Wong et al., 2009*).

More so than other psychiatric conditions, there is the additional impact of diagnostic uncertainty in the early stages with psychosis, together with uncertainty about prognosis and patient behaviour (*Askey et al., 2007*). It has been broadly estimated that approximately 40% of individuals with psychosis will be living at home with family during the early stages of illness, with 60-70% remaining in close contact with relatives (*Addington et al., 2005; Garety & Rigg, 2001*). Families are often required to maintain high levels of vigilance

during this period, particularly with regard to medication, as adherence is lower than at other stages (*Coldham et al., 2002*). Carers are known to find the inconsistent trajectory of the illness difficult and this can contribute to frustrating deliberations over whether some behaviours are symptomatic or not (*McCann et al., 2011*). Negative symptomatology in particular has been associated with poor carer understanding and increased carer distress (*Tucker et al., 1998; Birchwood & Cochrane, 1990*). This may be a more prominent feature for individuals at first episode and may contribute to the greater levels of distress reported by carers during early stages (*Birchwood et al., 2000; Tennakoon et al., 2000*). Moreover, lifetime risk of suicide in individuals with psychosis is estimated at eight times higher than the general population (*Hor & Taylor, 2010; Hawton et al., 2005*) and age standardised mortality is approximately doubled (*Brown et al., 2010; Saha et al., 2007*). By contrast to other conditions, in schizophrenia suicide risk is much more likely during the early stages of illness (*Power et al., 2003*).

For these many reasons, there has been a call for a dedicated psychosis carers' service (*Kuipers, 2010*). A conservative estimate based on Census data and the lower error margin of prevalence statistics suggests that up to 120,000 people in the UK may currently be caring for individuals with psychosis (*Kuipers, 2010*). This role has been associated with dwindling social networks and increased isolation at a level that distinguishes it from caregiving for long term physical disease e.g chronic heart conditions (*Magliano et al., 2005*). The age of onset is at a stage where many parents would be expecting individuals to be progressing towards independence (*Onwumere et al., 2011*). For those who would classify as the 'sandwich generation' (*Riley & Bowen, 2005*), looking after both parents and children at the same time, there may be a critical impact of taking on this unexpected extension of their caring role, whose commitment may be lifelong and continuous (*Clemmensen et al., 2012*). In addition, for certain carers the illness may have been anticipated as a result of family history of illness or indeed being service users themselves. The impact of their 'fears coming true' can be immense (*Barker et al., 2001*). These issues bring into sharp relief the notion of

carers having their own independent needs (Kuipers, 2010) in the context that the demands of their caregiving role may not even be their most pressing issue (Jones, 2009).

Notwithstanding these particular stresses, individuals desire to, can and do adapt to show incredible strengths in their roles (Sin *et al.*, 2005). Evidence suggests that the way in which people appraise their caregiving roles and their relative's behaviours dictates the levels of stress they feel and is the best predictor of their wellbeing (Martens & Addington, 2001). Furthermore, over time and with evidence-based support, carers report improvement in their levels of distress and therefore the quality of their relationships with patients (Addington *et al.*, 2005).

### **3.3 Expressed Emotion**

#### ***Development of a construct: empirical observation and measurement***

Expressed Emotion (EE) was developed in families living with psychosis and is the most widely established and validated outcome measurement used to assess the quality of social interaction between carers and care recipients in caregiving relationships (Van Humbeeck *et al.*, 2002). The term is not intended to capture emotional expressivity *per se* (Hooley & Gotlib, 2000) but represents five specific measures of the frequency and intensity of positively and negatively valenced statements made by a main caregiver when discussing their unwell relative. Measurement of EE is traditionally conducted by rating responses given in an extensive interview with caregivers (Wuerker, 2000). This has since been modified and shortened (Camberwell Family Interview, CFI, Vaughn & Leff 1976a). Despite ratings being based on the responses of caregivers, EE is recognised as a measure of social interaction in which patients and carers are '*involved in a system of mutual influence.*' (Hooley & Gotlib, 2000, p.136). EE has additionally been examined within formal care contexts to assess the quality of staff-patient relationships (Berry *et al.*, 2011; Endley & Berry, 2011; Moore & Kuipers, 1999).



The Camberwell Family Interview was developed in the 1960s by George Brown, Michael Rutter and colleagues at the Institute of Psychiatry during a series of experiments that had at their outset a central aim of identifying whether or not emotions in ordinary family relationships could be measured objectively and accurately (*Hooley, 2007; Brown & Rutter, 1966*). In an early study they observed that male patients, largely with a diagnosis of schizophrenia, reported better psychiatric outcomes one year after discharge if they had returned from hospital to live in supported accommodation or with siblings as opposed to with parents or partners (*Brown et al., 1958*). Moreover, the amount of contact they reported with close relatives was also related to psychiatric outcomes (*Hooley, 1985; Brown et al., 1958*). These findings were suggestive about the role that familial relationships may play in recovery and inspired follow-up studies examining specific aspects of the home environment and their association with patient outcomes (*Hooley, 2007*).

The group went on to test their developing semi-structured interview with relatives on their own, patients on their own and relatives and patients together using a controlled, prospective experimental design, in a study of 128 male patients with schizophrenia being discharged from hospital (*Brown et al., 1962*). Information was collected at three time points, upon discharge, two weeks later and a year later. Ratings of 'Emotional Involvement' or hostility expressed by a key relative alone at interview were found to have the strongest association with psychiatric outcomes at follow-up, even when severity of disturbance at discharge was taken into account (*Brown et al., 1962*). Individuals were split into dichotomous groups representing high or low emotional involvement. Those who had returned to live with relatives who were rated in the high group were significantly more likely to have experienced a relapse at 1-year follow-up than those who were rated as low 'Emotional Involvement'. The previous association with type of accommodation however was not replicated (*Brown et al., 1962*). These initial results led to the development and specification of the present day empirically-derived EE construct (*Brown et al., 1972*), as well as to the validation and modification of the CFI interview (*Rutter & Brown, 1966; Vaughn & Leff,*

1976a), and to confirmation of the association between living in a high EE environment and relapse in schizophrenia (Brown et al. 1972, Vaughn & Leff, 1976a).

### ***The indices of EE***

The five core scales now used for EE ratings comprise criticism, hostility, emotional over-involvement, warmth and positive comments (further specific details on administration and rating of the Camberwell Family Interview are given in the measures section in **Chapter 7, p.140**). The criticism scale is rated according to the number of comments made by the caregiver that demonstrate anger and frustration with the patient's behaviour either judged by tone of voice or direct statement. For example in a quote from the present project:

*'and there's days when everything is a different stage of f\*\*\*ing pink and I just look at her and I think you look like a schizophrenic. And then we'll argue over that 'cause I'll say maybe it's not a good idea to wear this or that. She doesn't like it and she won't accept it, so I say to her I'm not going out with you if you look like that.'*

***Mother, 50, white Irish, C149***

Hostility is associated with criticism as a scale, and is rarely rated in the absence of criticism. However, it is coded categorically as expressed or not expressed. It may be interpreted as an extension of severe criticism but is intended to capture independently the degree to which a caregiver displays resentment and animosity towards the individual themselves rather than merely their behaviours or actions. This may include rejection of the patient altogether (Leff & Vaughn, 1987). For example:

*'she's never bothered with anyone, she's just a loner, she's always just that sort of person, she's always been the way she is...so I've gone through quite a lot and when I say a lot, she accuse people of stealing her stuff. It's not funny. I mean she comes in with things. That was the main problem she was chucking out all my stuff...so I'm living through hell. If I'm not careful and get rid of her out of my house sometime soon I'm going to go mental too.'*

***Mother, 55, black Caribbean, C256***

Emotional over-involvement (EOI) is a more complicated and subtle construct that reflects a number of different reported behaviours associated with extreme over-concern in the caregiver, including intrusive attempts to control patient behaviour, devoted or self-

sacrificing behaviours, over-protectiveness and anxiousness. Studies suggest that EOI is more frequently reported in parental than in spousal relationships (Goldstein *et al.*, 2002).

*'I give him cigarettes just to sort of control the situation and help him. I know it's not the answer but I have a digital safe where I lock cigarettes and money up, so money and cigarettes and cannabis are a continual issue, money I have to control, I try and control the cigarettes, I try and control the money.'*

**Father, 68, white British, C240**

These three negative subscales, criticism, hostility and emotional overinvolvement, are used to generate an overall rating of high or low EE. Carers can be rated as high EE based on one above threshold rating on any of the scales of Criticism, Emotional Overinvolvement or Hostility. Studies suggest that a rating of high EE with just one main caregiver remains predictive of relapse in patients and EE has been interpreted as a wider measure of the emotional climate of a patient's immediate household or social support system (Hooley, 2007). Expressions of Warmth, including empathy and concern about the patient, for example, *'he is so lovely and he's such a good person and he doesn't deserve it.'*, as well as Positive Comments about their character or behaviour are additionally coded from the interview.

#### ***Predictive utility of high EE and the negative indices***

Since the initial studies, there have been numerous replications of the association between high EE and relapse in schizophrenia, with relapse being variably defined. Some studies have used rehospitalisation as an index of psychiatric outcome (Cechnicki *et al.*, 2013; Marom *et al.*, 2005). However, Hooley (2007, p. 333) noted that relapse is best conceptualised as a *'return of clinically significant symptoms based on an independent assessment with structured clinical interview'*. This they explain is because hospitalisation can be influenced by other variables including a family's ability and willingness to manage the illness at home. Following on from several aggregate analyses of findings (Kuipers & Bebbington 1994; Kavanagh, 1992; Parker & Hadzi-Pavlovic, 1990), in 1998 Butzlaff and Hooley published the most widely-cited meta-analysis on Expressed Emotion and

psychiatric relapse. They reported on 27 studies in schizophrenia that had used the CFI interview with a family member to measure prediction of relapse over a period of 9-12 months (*Butzlaff & Hooley, 1998*). Confirmatory findings were reported in 24 of these studies. These were conducted with first-episode groups and those defined as medium and high illness chronicity based on illness length and number of hospitalisations. The meta-analysis produced a weighted mean effect size of  $r = .31$  for the association between EE and relapse in schizophrenia, which the authors explain reflects an increased likelihood of experiencing a relapse of approximately two-fold for those individuals returning to a high EE environment versus a low EE environment. This is consistent with previous reviews (*Kuipers & Bebbington, 1994; Kavanagh, 1992*).

Both emotional overinvolvement and criticism are predictive of relapse in schizophrenia, as well as poorer recovery and treatment outcomes across a range of physical and mental health conditions including depression and eating disorders (*Hooley, 2007*). Yet, the predictive utility of the different dimensions varies across conditions, with criticism being ‘conventionally regarded as the principle scale’ (*Wearden et al., 2000, p.637*). The cut-off criteria used to designate high EE also vary across studies (*e.g Nomura et al., 2005*). These have typically been based on median values or those that best predict relapse in the literature (*Bebbington & Kuipers, 1994*). However, adherence to a standard increases comparability and reduces the likelihood of reports of spurious significance (*Bebbington & Kuipers, 1994*).

#### ***Predictive utility of the positive dimensions of EE***

It has been claimed that comparatively little attention has been paid to the potential predictive or clinical utility of the positive dimensions of EE (*Michelson & Bhugra, 2012, Bhugra & McKenzie, 2003*). Yet high warmth is considered a core feature of positive caregiving relationships (*Kuipers et al., 2010*) and since the early EE studies warmth has been indicated as protective in the course of illness (*Bebbington & Kuipers, 1994; Brown et al., 1972*). More recently warmth has been associated with improvement in social functioning in at-risk groups over a period of 3 to 6 months (*Schlosser et al., 2010; O'Brien*

*et al.*, 2006), as well as reduced likelihood of relapse in patient populations (López *et al.*, 2004; Ivanović *et al.*, 1994; Bertrando *et al.*, 1992). Cross-cultural studies suggest that variability in the warmth dimension of EE may characterise different ethnic groups (Hoste *et al.*, 2012) and there has been interest in conceptualising its influence on carer and patient outcomes (Grice *et al.*, 2009). For example, within Mexican American groups curvilinear models show that high warmth expressed alongside EOI may act as a buffer to the negative effects of acutely emotionally overinvolved interactions (Singh *et al.*, 2013; Breitborde *et al.*, 2007). In addition, although it has yet to be tested, there have been calls in the literature for an examination of the potentially moderating role of warmth within critical caregiving relationships (Michelson & Bhugra, 2012; Bhugra & MacKenzie, 2003). The coexistence of warmth and criticism has been noted as typifying normative familial relationships in certain countries, for example Indonesia (Subandi, 2011) and was observed to be a feature of low EE relationships, even in early studies examining EE in countries outside of the UK (Leff *et al.*, 1987).

For 30 years or so after the original EE findings, research concentrated on verifying the validity of high EE in predicting relapse. Since then certain studies have suggested that the effect size may not be as large as originally presumed (Parker & Hadzi-Pavlovic, 1990) and that the relationship between the dimensions and outcomes may vary across cultures (Bhugra & MacKenzie, 2003) and disorders (Hooley, 2007). However, the evidence remains relatively robust with confirmatory findings from a majority of studies conducted across Europe (Kuipers, 1992).

***Mechanism of action: does EE have an independent effect on patient outcomes?***

In 1998, Butzlaff and Hooley called for a moratorium on research into the EE-relapse link in favour of advancing understanding of the mechanisms: how and why high EE in carers might relate to patient relapse. One of the first issues to be considered in understanding EE was whether or not its constituent dimensions simply measure reactions to patient morbidity (Kuipers *et al.*, 2006b; Leff *et al.*, 1985). In its most extreme interpretation this would

assume that high EE interactions between carers and patients bear no causal influence on patients' thoughts, feelings and behavioural outcomes. Some studies have reported an association between patient symptoms and Expressed Emotion cross-sectionally (*Hooley, 2007*). Although the direction of influence is unclear, high EE has correlated with behavioural disturbances including aggression (*Brown et al., 1972*) and patient inactivity (*King et al., 2003*). In the earlier stages of illness it has been suggested that high EE may reflect familial distress in responding to the crisis of a family member developing illness more than an enduring quality of social interactions between carers and patients in which EE influences patient response (*Patterson et al., 2005*). However, the majority of follow-up studies conducted over 6-12 month periods either report no association between EE and patient illness characteristics at baseline or an independent predictive effect of EE on relapse, controlling for patient morbidity (*Hooley, 2007*). This is reported in shorter-term (3-12 months) follow-up studies in individuals At Risk of developing illness, first-episode groups and chronic presentation patients (*Meneghelli et al., 2011; Docherty et al., 2011; Cutting et al., 2006; Kuipers et al., 2006b; Heikkila et al., 2002*). It is a limitation of studies that look at the predictive effect of EE over long time periods (*Cechnicki et al., 2013; Lenior et al., 2002*) that EE is known to change over time (*Lenior, 2002; Wuerker et al., 2001*).

Further evidence suggesting EE exerts an independent effect on patient outcomes is derived from studies which assess the impact of family interventions on relapse rates. Intervention studies (designed to reduce high EE in family environments) began shortly after replication of the high EE-relapse association (*Leff et al., 1982, 1985; Falloon et al., 1982; Tarrier et al., 1989*). In these early studies individuals assigned to experimental groups receiving, in addition to medication, variable 'packages' of psychoeducation, coping-skills training, cognitive reappraisal and emotional processing were significantly less likely to relapse over 12 months than individuals receiving medication alone (*Lam, 1991*). Whilst it remains unclear whether Low EE environments prevent or merely delay relapse (*Kuipers & Bebbington, 1988; Hogarty et al., 1986*), a series of randomised controlled trials (RCTs)

now support the efficacy of Family Interventions (FI) for psychosis compared with standard care (*Lobban et al., 2013; Álvarez-Jiménez et al., 2011a; Onwumere et al., 2011; Bird et al., 2010; Kulhara et al., 2009; Carrà et al., 2007; Magliano & Fiorillo, 2007; Ran et al., 2003*). The Cochrane Review of Family Interventions in Schizophrenia (2010) included an updated meta-analysis of 53 RCTs (*Pharoah et al., 2010*) and the recently updated NICE guidelines (2009) for Schizophrenia, includes additional sub-group analyses exploring characteristics of the trials, such as the inclusion of the patient within groups sessions and applications within first episode groups (*Bird et al., 2010; NICE, 2009*). These reviews suggest that FI programmes can have a positive effect on levels of Expressed Emotion as well as service use, medication adherence, hospital readmission and frequency of relapse.

This evidence supports a causal role for caregiving relationships characterised by high EE in precipitating relapse in psychosis. However, families may benefit from therapeutic interventions in many ways and associated improvement in clinical outcomes for patients are not always predicated on changes in EE (*Miklowitz, 2004*). There is no evidence that Expressed Emotion measured after a first-episode equates to prior poor relationships and no evidence that high EE relationships cause psychopathology *de novo*. A distinction can thus be made between the interpretation of EE as a relationship variable of utility in guiding clinical interventions, as opposed to a risk factor for psychosis, that has in the past contributed to the blame families can feel (*Hooley, 2007; Lam, 1991*).

***Mechanism of action: physiological and psychological responses in patients to EE***

In their original studies Brown et al. (1972) hypothesised that Expressed Emotion may affect patients by increasing levels of arousal, overstimulating the patient and leading to behaviours such as social withdrawal (*Venables & Wing, 1962*). This theory has subsequently been conceptualised within more complex diathesis-stress models, in which EE is understood as a psychosocial stressor in schizophrenia (*Hooley & Gotlib, 2000; Nuechterlein & Dawson, 1984*). Tarrier and colleagues conducted a number of experimental

studies (*Tarrier & Turpin, 1992*) looking at the physiological response of patients (blood pressure levels and electrodermal skin conductance) in the home when alone, in the company of an experimenter and in the company of a high EE relative. They reported that sustained increases in levels of physiological arousal were recorded only when in the company of a high EE but not low EE relative (*Tarrier et al., 1988; Tarrier & Barrowclough, 1987; Tarrier, 1979*). Sturgeon et al. (1984, 1981) recorded similar results in a lab setting.

In a separate body of evidence, individuals with psychosis who were not in an acute condition have been shown to perceive accurately critical interactions with caregivers (*Renshaw, 2008; Bachmann et al., 2006*), despite potential emotional processing deficits (*Scazufca et al., 2001; Scott et al., 1993*). They have reported feeling more stressed by interactions with high EE relatives than low EE relatives (*Cutting et al., 2006*) and have recalled more stressful memories from interactions with high EE by comparison to low EE relatives (*Cutting & Docherty, 2000*). Both anxiety and sensitivity to stress in patients have been shown to mediate the relationship between EE criticism and psychotic symptom exacerbation (*Docherty et al., 2011, 2009; Cutting et al., 2006, Kuipers et al., 2006*). Moreover, perceived criticism from caregivers has been directly associated with increased anxiety and depression in patients (*Tomlinson et al., 2013*).

More recent studies have applied neuroimaging techniques in studying physiological responses to critical or emotionally over-involved vocal stimuli in patients. Using functional magnetic resonance imaging (f-MRI) to monitor changes in neural blood oxygen level, Rylands et al. (2011) reported enhanced activation of brain regions associated with processing of aversive stimuli (namely in the amygdala, temporal pole, inferior frontal gyrus and anterior cingulate) when participants listened to personally relevant critical comments from a relative, as opposed to neutral comments from a relative or critical comments from matched strangers whilst in the scanner. The study was conducted in a small sample of 11 patients and lacked a control group which would enable comparison regarding the



abnormality of response. However, the results are suggestive of differential neurobiological responses to high EE interactions. This hypothesis is supported by the findings of Premkumar and colleagues (2012), who compared f-MRI activation maps to visual depictions of social rejection, acceptance and neutral scenes, in low Schizotypy (LS), high Schizotypy (HS) and control groups. Higher sensitivity to rejection was recorded in HS participants and altered activation by comparison with LS and control groups of the dorsal anterior cingulate cortex. This brain area has been implicated in regulation of the salience of perceptual cues. Putative neural pathways responsible for mediating responses to Expressed Emotion have also been examined in individuals with a history of depression and borderline personality disorder by comparison to controls (*Hooley et al., 2010; Hooley et al., 2005*). There is also some evidence indicating potential candidate genetic polymorphisms in mediating cognitive responses in those with schizophrenia to critical exchanges with their family members (*Kéri et al., 2009*).

Patients' emotional and cognitive responses to aversive environments, such as difficult family environments and high EE interactions, have therefore been incorporated into cognitive models of psychosis (*Garety et al., 2007, 2001*). With these potential pathways to distress and symptoms of psychosis delineated in patients a complementary body of evidence has focused on understanding cognitive correlates of high Expressed Emotion in carers, with a view to understanding better the development of high EE relationships in carers.

### 3.4 Impact of Care, previously called the ‘burden’ of care

#### *Carer appraisals of burden: course and stability*

High EE relationships have been associated with carer burden and in particular self-reported burden, as appraised by carers themselves (*Carrà et al., 2012b; Möller-Leimkühler & Wiesheu, 2012; Kuipers et al., 2006b; Scazufca & Kuipers, 1996, 1998*). Perceptions of burden have been shown to be comparable among those caring for relatives At Risk of illness and those caring for relatives with a recent onset of psychosis (*Wong et al., 2008*). There has been no systematic review of evidence on the course of subjective burden in psychosis carers, and as with EE, burden may not be stable over time (*Awad & Voruganti, 2008; Möller-Leimkühler & Obermeier, 2008; Ohaeri, 2003*). However, there is some evidence of a potential decrease in burden 1-2 years after first onset of illness (*Möller-Leimkühler & Obermeier, 2008; Magliano et al., 2000*) which has been explained in terms of adaptation to loss (*Patterson et al., 2005*) as well as the acquisition of improved coping skills and increased social support (*Möller-Leimkühler, 2005; Magliano et al., 2000*). More positive appraisals of caregiving have been reported in carers of those with longer term illness (*Onwumere et al., 2008*). Yet there is also evidence to suggest that levels of distress in carers may show little change from index to follow-up over as long as 15 years (*Brown & Birtwistle, 1998*).

#### *Differential association between facets of burden and the indices of EE*

High EE is associated with overall subjective burden even at first episode (*Raune et al., 2004*). However, not in all studies (*Patterson et al., 2005*). Conflicting evidence may in part be explained by the profile of EE indices characterising the ‘high EE group’ in the studies in question. Patterson et al. (2005) report a significant association between subjective burden and high EE based on EOI but not criticism in early episode. This is consistent with theories suggesting that some elements of EE such as EOI may represent attempts by carers to cope (*Patterson et al., 2005, Van Os et al., 2001*). There is some evidence to suggest that levels of

worry about patients in the early stages of illness are as high as in carers of those with long term illness. However, anger may not be as prevalent (Wong *et al.*, 2008).

Few studies consider the individual components of subjective burden and their differential association with EE indices. Raune *et al.* (2004) reported that within early episode carers ‘perceived loss’ and ‘difficult behaviours’ were the facets of burden driving an overall significant association with high EE. At other stages in the course of illness perceived problems with social functioning for example are associated with high EE (Scazufca & Kuipers, 1998; Smith *et al.*, 1993; Barrowclough & Tarrier, 1990). In early studies Vaughn and colleagues (1976b) noted a subset of Low EE families in inner city deprived areas in which carers were characterised by ‘burnout’ rather than low levels of burden. More recently and in line with this, EOI and warmth have been shown to predict worse self-reported mental health in a sample of Mexican American carers of individuals with schizophrenia at 13-month follow-up (Breitborde *et al.*, 2010, 2009a).

#### ***Positive appraisals of caregiving and EE***

A more detailed investigation of the component facets of low burden, or positive appraisals of caregiving (for example finding meaning or reward in the caregiving relationship) and their relationships with EE is also lacking within psychosis research (Bauer *et al.*, 2012; Kate *et al.*, 2012; Kulhara *et al.*, 2012). However, low EE relationships have always been descriptively characterised by tolerance, acceptance and warmth (Dorian *et al.*, 2008; Vaughn & Leff, 1985). Positive appraisals of caregiving may have an independent influence or interact with negative appraisals in influencing relationship dynamics and communication (Kulhara *et al.*, 2012). A number of studies report an association between negative and positive appraisals of caregiving (Harvey *et al.*, 2001; Szukler *et al.*, 1996). The quality of the relationship between carer and care recipient prior to illness is also relevant to levels of reported burden or appraisals of caregiving (Kuipers *et al.*, 2010, Lauber *et al.*, 2003; Szukler *et al.*, 1996). It is not clear however to what extent some of the constructs proposed to constitute positive experiences of caregiving are differentiable from other concepts, for

example coping skills. Szmukler et al. (1996, p.147) noted this point in explaining that '*the link between appraisal and coping is circular and mutually interactive*'.

### ***Development of negative appraisals of caregiving (correlates)***

In understanding the development of perceptions of burden in carers a number of studies have analysed the relationship with patient illness characteristics (*Rafiyah, 2011*). There appears to be no consensus on whether any specific cluster of symptoms has the greatest impact on reported carer burden. However, effective drug treatments and improved clinical outcomes have been shown to reduce the burden experienced by families (*Perlick et al. 2010*). Some studies report that positive symptoms and disruptive behaviours are more burdensome for carers (*Carrà et al., 2012b; Grandon et al., 2008; Wolthaus et al., 2002*) while others report negative symptoms such as apathy, anhedonia and social withdrawal to be associated with greater burden (*Dyck et al., 1999*). Many report both (*Roick et al., 2007; Magliano et al., 1998; Provencher & Mueser, 1997*). There is however fairly consistent agreement that increased severity and chronicity of symptoms predicts higher subjective burden (*Rafiyah, 2011, Hjärthag et al., 2010; Awad & Vorunganti, 2008; Lowyck et al., 2004; Birchwood & Cochrane, 1990*). Trauma symptoms have been reported in at least one third of carers of individuals with psychosis (*Barton & Jackson, 2008*) and in potentially up to 50% of those experiencing moderate to severe levels of verbal aggression from their unwell relative (*Loughland et al., 2009*).

### **3.5 Attributions**

Investigations into the form and content of carers' evaluations of patient behaviours and the meanings they attach to events has offered another framework through which to conceptualise the development of high EE interactions and negative appraisals of caregiving. An 'Attributions model' of EE, based on carer beliefs about the controllability and intent of patient behaviours, is credited to Hooley (1997,1985) who acknowledges earlier proponents and theoretical contributions.

For example, Vaughn and Leff (1985) noted from clinical experience that low EE relatives were more likely to believe in the legitimacy of patient illness. Greenley (1986) also reported, in a re-examination of data from Brown, Birley and Wing (1972), that high EE families were less likely than low EE families to attribute difficult behaviours to genuine illness (*Barrowclough & Hooley, 2003*). Hooley (1987) expanded on this idea by examining whether certain symptoms, namely negative symptoms that might be more likely to be considered extensions of personality, and problems of impulse control like substance abuse, would predict lower marital satisfaction in spouses of patients with schizophrenia than other difficult behaviours. Their hypothesis was confirmed, and although the researchers acknowledge that attributions were not measured directly, the study was the first attempt to test an attribution based-model of EE (*Barrowclough & Hooley, 2003*).

Brewin and colleagues (1991) went on to suggest a theoretical context, in the form of Weiner's '*attribution, emotion, behaviour*' model (1985), to explain the links between carers' cognitive and emotional representations of illness behaviours and their social interactions with unwell relatives. According to this theory, negative and unexpected events result in a spontaneous search for causal meaning in humans, and associated emotions are generated that relate to the likelihood of success and mastery over a functional outcome (*Weiner, 1985*). Appraisals of events associated with a relative developing psychiatric illness are understood in simplified terms as involving two stages: first an evaluation of the valence of the event '*is it good or bad*' and second the initiation of attributional assessments of causality (*Barrowclough & Hooley, 2003*). These attributions are considered to play a significant role in determining discrete emotions in carers and resultant behaviours (*Hooley, 1987*).

### ***Measurement of attributions***

A number of self-report and observer-rated methods exist by which to analyse attributions. The Leeds Attributional Coding System (*LACS; Stratton et al., 1988*), which is used to assess five dimensions of causality from Camberwell Family Interview transcripts, is the

most common, and is considered superior in its ecological validity because it rates spontaneous causal attributions made in naturally occurring speech (*Barrowclough and Hooley 2003*). An attribution is defined according the LACS as ‘any answer to the question “Why?”’ (*Barrowclough & Hooley, 2003*). Using the LACS, causal attributions are rated on the following continua: ‘*Internal-External*’: the extent to which the event is considered a feature of the environment or the individual themselves. ‘*Stable-unstable*’: whether the cause is considered enduring or transient in its effects. ‘*Controllable-uncontrollable*’: could the individual within reasonable effort margins control the behaviour or outcome. ‘*Personal-universal*’: does the individual believe that something particular to the person governed the relationship between the cause and its effects or would the situation be the same for anyone, and finally ‘*Global-specific*’: is the cause associated with an isolated or specific outcome or diffuse and global outcomes.

#### ***Predicting EE: control attributions and blame***

The greatest amount of evidence in support of the utility of an attributions approach to understanding EE behaviours relates to the controllability dimension. A decade ago Barrowclough and Hooley reviewed 13 existing studies that investigated differences in the content of attributions made by relatives displaying high EE versus low EE characteristics, or in some cases higher and lower distress scores (*Barrowclough & Hooley, 2003*). A consistent finding was reported that individuals rated as high EE on the basis of criticism or hostility were significantly more likely than individuals rated as low EE to consider their relative’s difficult behaviours as controllable (*e.g Weisman et al., 2000; Barrowclough et al., 1994; Weisman et al., 1993*), and their causes as internal, personal and stable (*Yang et al., 2004; Brewin et al., 1991; Hooley & Licht, 1997*). This finding was, and has since been, observed in carers of individuals with schizophrenia (*Breitborde et al., 2009b; Weisman et al., 1998; Barrowclough et al., 1994*), carers of those with other conditions, including children with learning difficulties and adults with post-traumatic stress disorder (*Lancaster et al., 2013; Wasserman et al. 2010; Barrowclough et al., 2008; Bolton et al., 2003; Tarrier*

*et al.*, 2002; Wendel *et al.*, 2000; Hooley & Licht 1997), as well as in other cultures (Yang *et al.*, 2004; Weisman *et al.*, 2003). It has also been suggested that individuals with a diagnosis of schizophrenia may be more likely to be blamed by carers for their difficulties than individuals with other conditions, for example autism (Wasserman *et al.*, 2010). The researchers speculated that the earlier presentation of symptoms of autism in childhood may serve to legitimatise the diagnosis more than schizophrenia. Barrowclough *et al.* (2005) suggested that problems associated with impulse control in schizophrenia, for example high co-morbid substance use, may give rise to more internal, controllable and personal attributions, collectively referred to as '*responsibility attributions*' due to their co-occurrence (Barrowclough *et al.*, 2005).

#### ***An attributions model of high EE***

There is tentative evidence to suggest that response patterns associated with the various dimensions of high EE, namely criticism, hostility and emotional-overinvolvement may be differentiable in terms of attribution profiles. Barrowclough *et al.* (1994) proposed that carers displaying hostile reactions when describing patients also report a higher frequency of '*responsibility attributions*' than those who are critical but not hostile. In addition, Hooley and Licht (1997) and Brewin and colleagues (1991) reported that hostility in carers is associated specifically with higher internal attributions made about patient symptoms and fewer contributory causal factors, leading to a greater apportioning of blame. By contrast, attributions made by carers with high levels of emotional over-involvement were very similar to low EE carers (Yang *et al.*, 2004; Brewin, 1994). Barrowclough *et al.* (1994) reported that emotionally overinvolved carers were 'even' less likely to blame their unwell relatives for their difficulties than low EE carers.

Synthesising these findings within an attributional model, Hooley (1987) has suggested that high EE reactions in carers may be conceptualised as different methods by which people attempt to cope with distress. Highly critical and hostile reactions are conceived of as attempts to coerce patients into correcting their behaviours, given attributions of

controllability (Wuerker, 1994, Greenley 1986). Whereas emotionally over-involved carers are thought to engage in self-sacrificing attempts to control environmental factors that may modulate behaviour, due to their tendency to endorse external illness causes and to consider their relative unable to manage themselves (Barrowclough & Hooley 2003).

***The contribution of self-attributions in carers to the development of EE responses***

Some evidence is cited from analyses of carers' self-directed attributions. For example, self-blame in carers for their relative's illness has been associated with EOI behaviours (Wasserman et al., 2012; Peterson & Docherty, 2004; Bentsen et al., 1998; Barrowclough et al., 1996) as well as depressive symptomatology (McMurrich & Johnson, 2009; Bolton et al. 2003). In addition, McNab et al. (2007) reported in a first episode psychosis group that carers who were high on criticism EE attributed greater control to patients for their difficulties, and additionally were more likely to endorse the utility of what they termed '*person-focused*' critical statements. The study specifically examined carers' meta-cognitive beliefs about the efficacy of their own critical statements and self-sacrificing behaviours in moderating their relative's behaviour. The questions used in the study differentiated between carers' perceived utility of expressing dissatisfaction about isolated patient behaviours versus the individual 'as a person' in aiding their relative to overcome difficulties.

***Mechanism of action: does 'behavioural control' mediate the relationship between carers' attributions and patient response?***

Two further studies have employed a ratings scale devised to measure '*behavioural control*' from statements made in the Camberwell Family Interview (Vasconcelos et al., 2013; Hooley & Campbell, 2002). Vasconcelos et al. (2013) distinguish between mild, moderate and severe attempts to elicit '*directly influencing behavioural control*' versus '*buffering behavioural control*'. Examples of the former include polite requests, direct instruction, and at the more severe end of the scale, ultimatums. Examples of the latter include supervising, changing things that a patient has already done and restricting possessions or activities. Consistent with Hooley's (1987) model, '*direct behavioural control*' was hypothesised to



be associated with high EE criticism, and '*buffering behavioural control*' with high emotional overinvolvement. These hypotheses were confirmed by the study, however behavioural control was not associated with relapse in this sample. Using a different coding system Peterson and Docherty (2004) noted an association between statements of behavioural control and high EOI but not criticism in carers. Although in each of these studies ratings of behavioural control were conducted blind to the overall EE ratings, the issue of potential circularity in the ratings scales was not addressed by the researchers.

With a clear pathway or mechanism of action still to be identified, Barrowclough and colleagues proposed in 1994 that attributions may be a better predictor of relapse in patients than Expressed Emotion (*Barrowclough et al., 1994*). They reported in a sample of 51 patients with a diagnosis of schizophrenia recruited from an inpatient ward and 60 relatives, that internal and controllable attributions made a larger contribution to the prediction of relapse over a period of 9 months than EE. However, this finding has not been replicated (*Barrowclough et al., 2008; Lopez et al., 1999; Hooley & Licht 1997*). Moreover, in support of models that may consider '*Expressed Emotion a more proximal factor in the relapse process than attributions*' (*Barrowclough & Hooley, 2003, p. 871*) more recent studies confirm an association between carers' attributions of controllability for negative events and relative's perceived criticism; in community couples (*Peterson & Smith, 2011*) and in individuals with mixed diagnoses of Obsessive Compulsive Disorder, Panic Disorder and Agoraphobia (*Chambless et al., 2010*). Perceived criticism is hypothesised to lead to negative evaluations of self, erosion of self-worth and potentially depressive symptoms in patients (*Barrowclough & Hooley, 2003*). Barrowclough et al. (2003) present some statistical support that the relationship between carer criticism and increased positive symptoms in patients with psychosis may be mediated by negative self-evaluations. Notably however there are very few empirical studies that examine the impact of EOI behaviours from a patient perspective (*Medina-Pradas et al., 2011; Cutting et al., 2006*) and no known

studies examine specifically how this might feel to the patient or propose a potential pathway for its effect on relapse.

#### ***An attribution model of low EE***

From an attributions perspective, low EE or warmth in caregiving relationships has most frequently been explained simply in opposition to criticism and hostility in its relationship with responsibility attributions. Thus personal, controllable and internal attributions about negative events have been associated with low warmth in carers (*Bolton et al., 2003, Lopez, 1999, Barrowclough et al., 1994, Hooley & Licht 1997*). Although there have been more recent attempts to explore the cognitive responses of low EE carers through structured analyses of qualitative interviews (*Treanor et al., 2013*). Furthermore, in a development for the attributions framework Grice and colleagues (2009) examined the contribution that attributions about positive events might make to the development of both warmth and also EOI reactions in carers of individuals with psychosis. They reported that low EE carers were significantly more likely than high EE carers to acknowledge their relative as personally responsible for positive things in their life, for example making an effort around the house, engaging with treatment or finding work. In the study they looked at responsibility appraisals for both positive and more frequently negative events, and they examined the responses of carers displaying high levels of EOI behaviours, yet low levels of criticism, who rarely attributed responsibly to patients for anything. The researchers refer to the latter as ‘*victim appraisals*’ which they contrast with the ‘*survivor appraisals*’ of low EE carers who express high warmth and who focus on their unwell relative’s achievements in the face of difficulty.

#### ***A target for family interventions***

Although the link between carer attributions of causality for symptoms and patient distress is not direct, there is strong evidence to suggest carers’ causal beliefs influence emotional and behavioural reactions to patients. As a result, a number of family interventions for psychosis emphasise the importance of considering relatives’ beliefs about the illness in designing

treatment content (*Barrowclough & Tarrier, 1997*). Attributions of control in carers are not only related to constructs of relevance to patient outcomes but also to distress in carers (*Hui et al., 2011*). Most Family Interventions in psychosis include a psychoeducational component (*Lobban et al., 2013*). However, there is evidence to suggest that provision of information alone is insufficient to change attitudes in family members (*Berkowitz et al., 1984*) and moreover that existing attitudinal biases affect the processing of new information in the first instance (*Barrowclough & Hooley, 2003*). Targeting carer attributions in treatment is also more complex than simply reducing high controllability attributions. A study by Renshaw et al. (2006) for example underscores that too few attributes of control to patients in carers, and an overemphasis of external cause of illness, may contribute to patients' poorer engagement with behavioural therapies, by encouraging a potential to a 'sick role'.

### 3.6 Illness beliefs

#### *A self-regulation model of illness beliefs: theory and measurement*

A complementary strand of research has applied theories developed within health psychology to psychosis in order to consider a broader range of beliefs about illness that may influence carer and patient outcomes and their emotional interactions (*Fortune et al., 2005; Lobban et al., 2003*). Leventhal and colleagues' (1984) 'self-regulatory' model (SRM) is one of the most influential (*Weinman et al., 1996*). It proposes that when faced with a health threat individuals form cognitive representations of illness that predict health-related behaviours, relationships with health providers and resultant health outcomes (*Leventhal et al., 1997; Leventhal et al., 1992; Leventhal & Nerenz, 1985*). People are conceptualised as 'active problem solvers' who evaluate a health threat in a way that guides adaptation and coping responses (*Lobban et al., 2003; Leventhal et al., 1984*).

Five core constructs are presented in the SRM that taxonomise these representations. These comprise: first, a basic appraisal of what the illness 'is', this is referred to as *identity* and

includes an evaluation of experiences, symptoms and behaviours, labels and diagnoses, second is a representation of the *cause* of illness, its aetiology and whether causal factors are internal or external to the individual, third *cure-control* reflects the extent to which the illness manifestations are controllable by the individual or amenable to cure, fourth is a representation of the *consequences* of the illness and the extent of its personal, social and financial impact on the individual and those around them, and finally *timeline* comprises beliefs about the length of time the illness will continue and perceptions about its course.

Using the SRM framework illness beliefs have been extensively investigated across a range of medical conditions (Petrie *et al.*, 2007; Skelton & Croyle, 1991). Different measurement instruments have been used to examine and confirm the reliability and validity of the five core constructs in predicting emotional and practical responses to physical illness, and associated health outcomes (Hagger & Orbell, 2003; Bishop & Converse, 1986). For example, in a meta-analysis of 45 studies, illness representations were consistently associated with levels of distress in patients, their service use and medication adherence, even whilst controlling for symptom severity and other confounding factors (Hagger & Orbell, 2003). The Illness Perception Questionnaire (IPQ), developed by Weinman and colleagues (1996), in its original and revised versions for patients and carers (Broadbent *et al.*, 2006; Lobban *et al.*, 2005a, 2005b; Lobban *et al.*, 2004; Moss-Morris *et al.*, 2002) has emerged as a dominant method of assessment within mental health research (Baines & Wittkowski, 2012).

#### ***Application of the SRM to illness beliefs in severe mental illness***

In 2003 Lobban and colleagues published a review on the application of the SRM to the examination of illness beliefs in severe mental illness. They collated qualitative and quantitative studies across mental health conditions and suggested that whilst previous research may not have made explicit reference to a theoretical framework their results were interpretable in terms of the domains identified in Leventhal's (1984) self-regulatory model. The group suggested that, with appropriate modifications, the SRM may be a useful tool by

which to quantify cognitive representations of illness as applied to mental health conditions (Lobban *et al.*, 2003). Since this review, evidence has been gathering within psychosis samples in support of their claim. For example, the same group examined the utility of illness beliefs in predicting coping and functional outcomes over a 6-month period within a community sample of individuals with longer-term psychosis (Lobban *et al.*, 2004). As part of the study they developed a modified version of the Illness Perception Questionnaire based on qualitative interviews with patient populations that included for example the division of the *cure-control* dimension into beliefs about personal control over illness versus treatment control. In addition, the *timeline* domain includes items assessing beliefs about acute, chronic and cyclical illness course. They demonstrated that strongly held beliefs about the negative *consequences* of illness (for example ‘*my mental health problems have messed up my social life*’) at baseline were predictive of distress, depression and poorer self-reported quality of life at follow-up. The amount of variance accounted for by beliefs however was smaller in longitudinal than cross-sectional analyses. Notably they did not report an association with coping within this sample, and suggested that beliefs may have a direct effect on outcomes in patients (Lobban *et al.*, 2004). .

Furthermore, in a cross-sectional study, beliefs about the *identity*, *consequences* and *timeline* of illness predicted significant variance in levels of depression, anxiety and self-esteem in individuals interviewed within 3 months of discharge after a first episode of psychosis (Watson *et al.*, 2006). More recently using an alternative measure of illness beliefs, Acosta and colleagues (2013) confirmed an association between patients’ negative evaluations of their illness (poor expectations and control of illness and feeling stigmatized) and self-reported symptoms of depression and hopelessness in a schizophrenia sample (mean length of illness less than 10 years). Greater insight into illness in first-episode groups has also been associated with increased depressive symptoms, independent of overall psychopathology (Cotton *et al.*, 2012).

***Psychosis-specific issues in applying an SRM framework to illness beliefs***

The potential for illness belief models to aid in prediction of outcomes for patients, and improvement of treatment uptake and efficacy, is one of their most important applications (Petrie *et al.*, 2007). However, authors have advised against over-estimating the utility of the SRM framework as opposed to individual formulations for patients whose understanding of their illness and its personal meaning is necessarily more complex (Lobban *et al.*, 2003). In a demonstration of this point Kinderman and colleagues (2006) compared reported illness beliefs in a small sample of inpatients diagnosed with schizophrenia versus outpatients currently experiencing psychotic symptoms and outpatients in remission. Using thematic analysis of in-depth interviews, they identified differences in the way that psychosis samples conceptualised their illness, compared with established explanatory models of physical illness. Patients in remission appraised their experiences in a way that was consistent with conventional explanatory models, but individuals experiencing a current episode of psychosis did not identify separable illness entities from their present experiences. Kinderman *et al.* (2006) also noted the potential for participants to refer to previous periods of illness as transient episodes of irrationality that were not integrated into a sense of self but rather were dealt with by ‘sealing over’ or avoidant coping. A central conclusion from this study was therefore that mental health difficulties and psychosis in particular may compromise the ‘appraising self’ that underpins health belief formation (Kinderman *et al.*, 2006). People with psychosis may not always hold, or strive to hold, a consistent and coherent set of beliefs (Holzinger *et al.*, 2003). Hence it is proposed that the appropriateness of a health belief model in psychosis is dependent on the timing of assessment (Kinderman *et al.*, 2006).

Taking this point about illness severity and timing of assessment into account, Freeman *et al.* (2013) showed that patient beliefs about the causes of their illness, its chronicity and their perceived control over symptoms predicted uptake of a programme of cognitive behavioural therapy, in a sample of individuals who had experienced a recent first episode of psychosis,

over and above psychiatric symptomatology and insight at baseline. Stange and colleagues (2013) have also recently demonstrated that a pessimistic attributional style about the causes of illness was associated with a lower likelihood of recovery (defined as a decrease in depressive symptomatology below clinical thresholds) and a longer duration until recovery, independent of the effects of initial depression severity, in a sample of individuals with bipolar depression.

***Carers' beliefs about illness in psychosis: relationships with distress and EE***

Although in some cases carers may have mental health difficulties themselves, the use of conventional models of illness beliefs (the SRM) has been less controversial when applied to relatives of individuals with psychosis. On balance the evidence suggests that carers' wider illness perceptions are more likely to predict affect and outcomes for themselves rather than illness severity or functioning in patients (Kuipers *et al.*, 2010b). However, the relationships reported between carers' illness beliefs, EE behaviours and coping have not been totally consistent. Barrowclough and colleagues (2001) examined the reliability and validity of a modified version of the IPQ for carers of individuals with schizophrenia. The study included questions on carers' beliefs about the *consequences* of illness for themselves and their own perceived *control* over their relative's illness. In support of the validity of the scale they reported significant correlations between carers' cognitive representations about the *consequences* and *timeline* of illness and objective measures of the severity of patient illness. Additionally, they noted in carer-patient relationships in which the carer rated more severe *consequences* of illness for their relative, that patients perceived more negativity from their carer. Consistent with previous studies, carers who rated the illness as less amenable to *cure* or *control* by themselves or by patients, and believed it would follow a chronic *timeline*, were more likely to be classified as high EE or highly critical (Barrowclough & Parle, 1997).

Lobban and colleagues (2006) followed-up these results by examining discrepancies in illness beliefs held by patients and their carers and their role in predicting EE responses in

the caregiving relationship. The study was influenced by work by Heijmans et al. (1999) who had previously demonstrated in couples where one individual was suffering from a chronic endocrine disorder, that disagreement in their representations of illness (and in particular perceived *consequences* of illness) was associated with reduced marital satisfaction. Similarly, Lobban et al. (2006) recorded that greater discrepancies in illness beliefs held by schizophrenia carer-patient dyads were associated with high EE interactions.

However, this finding was not confirmed by Kuipers and colleagues (2007). In a sample of 82 carers of patients with psychosis, recruited at a time of re-emergence of positive symptoms, the researchers reported no significant correlations between overall EE status and ratings on any of the IPQ dimensions. The study was conducted as part of the larger Prevention of Relapse in Psychosis (PRP) Trial (Garety et al., 2008) and provided evidence for the association of pessimistic illness beliefs in carers (more severe *consequences*, less *controllable*, longer *timeline*) and carers' self-reported distress, depression and lower self-esteem. Furthermore, carers reported more mood problems when their views on the controllability of illness were divergent from their relatives' views. Consistent with findings from the study by Heijmans, the group also reported that carers were more pessimistic than patients about the *consequences* of illness. Moreover, the magnitude of the divergence in their ratings was predictive of EOI behaviours, controlling for criticism. In the cases in which this trend was reversed (i.e carers were more optimistic than patients) it was patients who reported higher levels of anxiety and depression and lower self-esteem.

The association between carers' wider beliefs about illness and carer distress has been confirmed by Onwumere et al. (2008), who investigated the links between illness beliefs and positive caregiving appraisals. The study reported that carers who believed that their relative (and they themselves) could exert more *control* over the course of illness were more likely to acknowledge rewarding factors in the caregiving relationship as opposed to carer burden. However, illness beliefs did not fully mediate the relationship between caregiving appraisals



and distress in this study. Fortune and colleagues (2005) also emphasised the relationship between negative illness beliefs and distress in carers, whilst exploring the role of coping in a cross-sectional study of 42 relatives of individuals with schizophrenia. Using hierarchical regression they demonstrated that illness beliefs and coping styles made an independent contribution to variance in carer distress, over and above demographics and primary and secondary appraisals of the impact of care. Furthermore, coping strategies characterised by greater positive reframing, less self-blame and greater acceptance were found to mediate the relationship between attributions of control to the patient for their condition and distress.

### **3.7 Coping**

#### ***Taxonomising coping strategies***

Conceptualising coping and its relationship with the affective styles of interaction that comprise Expressed Emotion was an early research priority within the field (*Kuipers & Bebbington, 1988*). Birchwood and Cochrane (1990) made a significant contribution to advancing coping theory, as applied to families caring for someone with a schizophrenia spectrum diagnosis, by creating a dimensional taxonomy of coping strategies used by carers. They noted the need for forthcoming studies to investigate relationships with EE. In interviews with 33 families, they identified seven different cognitive and behavioural strategies including coercion, avoidance, ignoring, acceptance and resignation. Moreover they underscored the importance of conceptualising carer coping as part of an interaction with patients. This is consistent with Lazarus and Folkman's (1984) stress-appraisal-coping model in which coping is conceived of as part of a dynamic process of responding to stress. In a follow-up study of college undergraduates preparing for an exam, Folkman and Lazarus (1985) demonstrated the significant contribution that 'Ways of Coping' made to variance in positive and negative emotional responses to stress. The researchers discussed elsewhere the bi-directional interactive relationship they envisaged between coping responses and emotion (*Folkman & Lazarus, 1988*). They also distinguished between two forms of coping: *problem-focused coping* and *emotion-focused coping*. The former refers to practical

strategies targeted at removing or altering the cause of stress, for example information gathering, planning and problem-solving and the latter focuses on regulating internal emotional reactions to the stressor including distancing, repression, avoidance or positive reappraisal. It is proposed that problem-focused strategies may be more likely to be used when the situation is appraised as amenable to change (*Lazarus & Folkman, 1991*) whereas emotion-focused strategies are more likely to be employed in cases of bereavement or loss, for example, in which individuals perceive that they can do nothing practical to improve the situation.

More recently, some studies that have examined coping strategies in terms of 'Avoidant' versus 'Active' coping (*Onwumere et al., 2011; Kuipers et al., 2006b; Raune et al., 2004; Scazufca & Kuipers, 1999*). Denial, behavioural disengagement, mental disengagement and drug use are examples of the types of coping strategies that have been defined as Avoidant (*Raune et al., 2004*). These have been contrasted with positive reframing, acceptance, and use of humour (*Carver et al., 1989*). On occasions the distinction has been referred to as 'Maladaptive' versus 'Adaptive' coping techniques (*Friedman-Yakoobian et al., 2009; Horan & Blanchard, 2003*). However this implies a false dichotomy. Elsewhere it is acknowledged that coping behaviours like mental disengagement may be effective in the shorter term, but not if a problem should persist (*Kuipers et al. 2010*).

#### ***Avoidant coping, distress and EE***

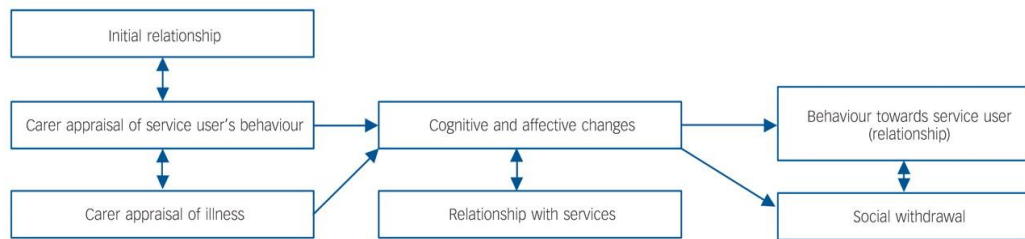
The most consistent finding across studies is of a positive association between Avoidant coping and carer distress - negative appraisals of caregiving or carer burden (*Cotton et al., 2013; Onwumere et al., 2011, Friedman-Yakoobian et al., 2009; Chadda et al., 2007; Kuipers et al., 2006b; Raune et al., 2004; Scazufca & Kuipers, 1999*). Moreover, Avoidant coping has also been shown to be related to high EE in carers in cross-sectional studies (*Cotton et al. 2013*), prospective studies (*Scazufca & Kuipers, 1999*) and in first-episode groups (*Raune et al., 2004*). Within a limited number of studies it is suggested that Avoidant

coping may specifically or more strongly predict emotionally over-involved responses in carers as opposed to critical responses (*Cotton et al., 2013, Scazufca & Kuipers, 1999*).

The causal interaction between coping and EE processes is recognised as necessarily complex (*Kuipers & Bebbington, 1988*). A number of studies have examined the extent to which coping styles change over time or illness course for carers (*Cotton et al., 2013; Onwumere et al., 2011; Gerson et al., 2011*). It has been hypothesised that this may explain changes in EE over time or predict stability (*Kuipers & Bebbington, 1988*). Some studies suggest that poorer coping is more common in the early stages of caring for someone with a recent diagnosis of psychosis (*Kartalova-O'Doherty & Doherty, 2008*) while others suggest that coping may deteriorate over time (*Cotton et al., 2013, Gerson et al., 2011*). There are however limitations associated with these studies including the cross-sectional or qualitative nature of their design and lack of a comparison group. In a single study comparing coping in groups of carers of individuals with recent and longer-term illness Onwumere et al. (2011) reported no association between length of time caring and coping strategies.

### **3.8 A cognitive model of caregiving in psychosis**

Integrating each of these lines of empirical inquiry within an EE framework, Kuipers and colleagues (2010b) have proposed a cognitive model of caregiving that presents testable hypotheses for interactions in appraisal and coping mechanisms (**Figure 3, overleaf**). The model supposes that carers can be helpfully categorised according to their behavioural reactions towards relatives as '*Positive*', '*Emotionally-overinvolved*' and '*Critical*' to guide interventions targeting carer distress. The authors have presented a profile of cognitive and emotional factors that leads to the development and maintenance of the divergent behavioural outcomes observed in each type. These cognitive and emotional factors have been identified from the literature reviewed above: carers' appraisals of their unwell relatives' behaviours, their models of illness and the coping resources they have available to them.

**Figure 3: A cognitive model of caregiving in psychosis**

*Kuipers et al., (2010); p.260*

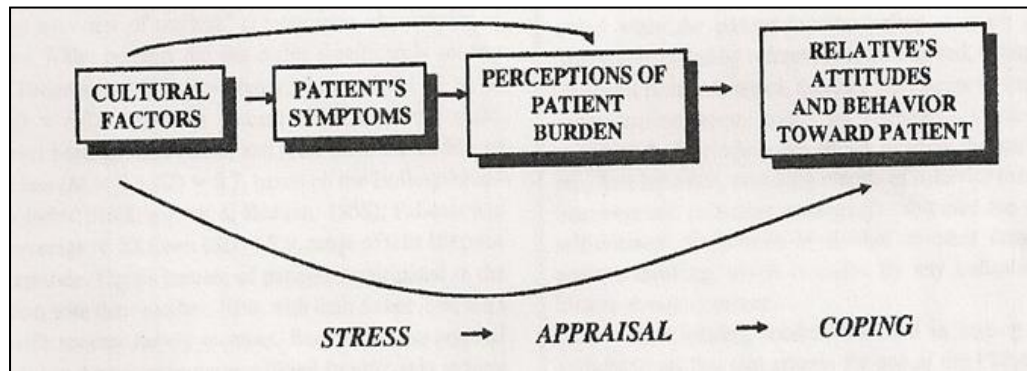
The model additionally acknowledges the role of the previous state of the relationship between carer and care recipient in influencing cognitive biases in the interpretation of behaviours and illness. Consistent with previous statistical evaluations of the relationships between factors in a stress-appraisal-coping model of caregiving the model presents a significant role for coping efficacy and loss of social support in predicting carer psychiatric morbidity (*Joyce et al., 2003; Joyce et al., 2000; Sz mukler et al., 1996, Anderson et al., 1984, Greenblatt et al., 1982*). Strong emphasis is placed on addressing carer distress, as family intervention studies in psychosis have typically focused on service-user outcomes (*Lobban et al., 2013*). Furthermore, a critical point in the presentation of the model is its focus on ensuring support for individuals responding positively to their caregiving role to maintain their own health. The authors recommend information, support and respite at the very least for ‘low EE’ carers.

## Chapter 4: Culture and caregiving

### 4.1 A sociocultural stress, appraisal, coping model of caregiving

Migration to Western countries and changes in demographics have led researchers to review the utility of models of caregiving as applied to ethnically diverse communities. To date most of this work has focused on caregiving relationships in older adults and has been progressed within the United States of America (*Knight & Sayegh, 2010; Scharlach et al., 2008; Sörensen & Pinquart, 2005; Pinquart & Sörensen, 2005; Janevic & Connell, 2001; Aranda & Knight, 1997*). In the UK, the 2011 Census recorded a five point decrease in the White majority population to 86% across the British Isles and to 80% in England and Wales combined. In London, the white British population (by contrast to white ‘Other’) has decreased from 58% in 2001 to 45% over the last decade. The ethnic composition of the older adult population is also changing. Ethnic minority groups in general have a younger age structure (*Weich et al., 2004*). However, a higher rate of growth in the elderly has been observed over the last 10 years in the black Caribbean population by comparison to other ethnic minorities (*Lievesley, 2010*). Most Caribbeans living in the UK emigrated in the 1950s and 1960s, prior to major influxes of people from other countries.

In addition to changing demographics on national and regional scales, within psychosis research it is the increased risk of developing the condition conferred by ethnic minority status that motivates a cultural approach (*Bhui & Tsangarides, 2008; Bhui & Sashidharan, 2003*). Rosenfarb and colleagues (2006b, p. 157) at the Alliant International University in California have proposed a ‘*sociocultural stress, appraisal, coping model of subjective burden and family attitudes towards patients with schizophrenia*’ (**Figure 4, overleaf**). Building on theoretical developments and empirical evidence in dementia research (*Knight et al., 2000*) they hypothesised that cultural factors would contribute to variation in the appraisal of patient behaviours and the caregiving role, as well as availability and efficacy of coping resources. They have proposed that this in turn determines the level of burden individuals experience from caregiving, and their resultant behavioural responses to patients.

**Figure 4: A sociocultural stress, appraisal, coping model of caregiving**

*Rosenfarb et al., (2006b); p.158*

Providing empirical evidence for their hypothesis, the group reported that white family members (N=79) were significant more likely than African American carers (N=92) to feel burdened by their caregiving role and to have rejecting attitudes towards their unwell relative, even controlling for illness severity and sociodemographic variables (*Rosenfarb et al. 2006a*). The authors acknowledged the limitations associated with using self-identified ethnicity as a proxy for cultural group membership. Yet the results were consistent with Knight et al.'s (2000) findings in dementia carers and their hypothesis that ethnicity or race may moderate stress appraisals.

Since then however comprehensive reviews of the literature suggest that the evidence regarding ethnic differences in perceived carer burden is highly conflicted and complicated by methodological limitations (*Dilworth-Anderson et al., 2002; Janevic & Connell, 2001*). Knight and Sayegh (2010) have subsequently updated their original model placing greater emphasis on the role that culture may play in influencing coping resources such as social support and coping styles rather than appraisals of burden. They propose familism, a measure of familial obligation, perceived family support and family values, as an example of a cultural value that varies across ethnic groups and may confer specific effects on caregiving processes (*Sayegh & Knight, 2011; Kim et al., 2007*). Lazarus and Folkman's core model (1984) of distress remains a common feature to conceptualisations of caregiving across ethnic or cultural groups (*Knight & Sayegh, 2010; Chun et al., 2007; Kim et al.,*

2007; Sörensen & Pinquart, 2005). However, greater attention is still frequently called for in the measurement and conceptualisation of culture and specification of the mechanisms and pathways via which it may shape appraisals and coping (Dilworth-Anderson *et al.* 2002; Janevic & Connell, 2001).

## **4.2 Definitions and measurement of culture**

### ***Definitions of culture***

Different definitions of culture abound in the literature and vary according to the research discipline to which they are being applied. A select few are noted here for their particular relevance to the processes specified in cognitive models of caregiving. In *Culture and Psychology*, Matsumoto and Juang (2011, p.15) refer to culture as '*a unique meaning and information system, shared by a group and transmitted across generations that allows the group to meet basic needs for survival, pursue happiness and well being and derive meaning from life.*' Political scientist, Lederach (1995, p.9), explained that '*culture is the shared knowledge and schemes created by a set of people for perceiving, interpreting, expressing and responding to the social realities around them*', and also LeBaron (2003, retrieved 2013) has described culture as narratives that '*give us messages that shape our perceptions, attributions, judgments, and ideas of self and other*'. Finally, the Center for Advanced Research on Language Acquisition (CARLA, 2013, retrieved 2013) at the University of Minnesota defines culture '*as the shared patterns of behaviours and interactions, cognitive constructs, and affective understanding that are learned through a process of socialization. These shared patterns identify the members of a culture group while also distinguishing those of another group*'.

### ***Using ethnicity as a proxy for culture***

Three approaches to the examination of cultural differences in caregiving processes are identifiable from empirical studies. As in the Rosenfarb *et al.* (2006a) study, the first uses ethnicity as a proxy for culture and examines ethnic group differences in appraisals and coping (e.g. Bhui *et al.*, 2008; McCabe & Priebe, 2004). This is contrasted with previous

conceptualisations of ethnicity which assume that ethnic group affiliation is simply an indicator of social disadvantage (Markides *et al.*, 1990). The approach assumes that, with appropriate control of potentially confounding socioeconomic variables, ethnicity implies cultural differences that will directly affect the appraisal of caregiving as stressful, and will change mediating variables like coping (Knight *et al.*, 2000). Ethnic group categories were first used in the UK in the 1991 Census and are based on self-identification (*Ethnic group statistics: a guide for collection and classifications*, Office for National Statistics, 2003). Ethnicity is typically considered to incorporate subjectively meaningful elements of race and culture (Shah *et al.*, 2004; Baumann, 1996) and ethnic groups are ‘composed of people who may or may not share the same race but do share common cultural characteristics including history, beliefs, values, food and entertainment preferences, religion and language.’ (Bhugra & Becker, 2005, p.17).

***Quantifying culture: the concept of acculturation and its measurement***

To address the limitations of using ethnic group membership as a proxy for culture, the second approach attempts to measure explicitly dimensions of culture as a construct and their association with variation in responses to caregiving. The concept of acculturation is introduced in this context (Koneru *et al.*, 2007). In one of the first attempts to operationalise this concept Redfield and colleagues (1936, p. 149) described acculturation as ‘those phenomena which result when groups of individuals having different cultures come into continuous first-hand contact, with subsequent changes in the original culture patterns of either or both groups.’ Acculturation measurement typically involves a self-report scale comprising cultural domains, for example language-use, religion and ethnic identification (Buddington, 2002; Snowden & Hines, 1999; Landrine & Klonoff, 1994; Suinn *et al.*, 1992). For each domain, individuals are plotted on a continuum between binary opposites that reflect ethnic culture of origin and mainstream culture (Gutmann, 1999). Early conceptualisations have regarded acculturation as a uni-directional process. For example Gordon (1964) proposed a model of acculturation as assimilation, whereby newly migrating



individuals were considered to lose gradually attitudes, values and behaviours associated with their culture of origin, whilst simultaneously adopting those of their new ‘host’ culture. This conceptualisation is considered to underpin the subsequent usage of terms like ‘modernisation’, ‘westernisation’ and ‘Americanisation’ (Salant & Lauderdale, 2003).

Within psychosis research, interest developed into the contribution that studying acculturation processes may bring to understanding increased vulnerability to illness within migrants and their descendents (Bhugra *et al.*, 2010; Koneru *et al.*, 2007; Koneru & Weisman de Manami, 2006). So-called ‘uni-dimensional’ models, and measurement instruments, have been criticised for their inability to capture the co-existence of integrated or bi-cultural identities (Ryder *et al.*, 2000). Early acculturation scales represented biculturalism with midpoint scores (Cuellar *et al.*, 1995). Yet it is noted that this fails to distinguish individuals who identify with both cultures from those who identify with neither (Mavreas *et al.*, 1989). The idea that the acquisition of new cultural norms and values necessitates a loss of culture of origin attributes also panders to a concept of culture as something passive that ‘without any conscious awareness we absorb’ (Bhugra & Bhui, 2007, xviii). In contrast to this notion, López and Guarnaccia (2000) argue that culture cannot be reduced to a simple set of beliefs or values that identify a group of people. They stress that development of culture must be understood as an intra-individual, dynamic process that is shaped by an individual’s engagement with their social network.

More recently bi-dimensional or multidimensional models that employ parallel continua reflecting both one’s ethnic ‘minority’ culture and ‘host’ culture have been employed in the study of acculturation (Ryder *et al.*, 2000). Berry (1997) developed the most widely-cited multidimensional framework (Bhugra *et al.*, 2010; Koneru *et al.*, 2007; Koneru & Weisman de Manami, 2006) which allows for individual variation along independent scales reflecting ethnic minority and ‘host’ cultural domains. The model is based on a revised definition of acculturation as ‘the dual process of cultural and psychological change that takes place as a result of contact between two or more cultural groups and their individual members’ (Berry,

2005, p.698). Berry identified four acculturation strategies within the model. *Assimilation* is thought to occur when an individual adopts values associated with the dominant culture, potentially at the expense of those already held. The opposite of this is *Separation* whereby new cultural values are rejected, old ones are maintained and interaction with other cultural groups may be avoided. A combination of the two strategies is classified as *Integration*. Loss of affinity with culture of heritage without engaging in new cultural values is termed *Marginalisation*.

***A role for acculturation processes in psychosis?***

The empirical evidence examining the links between acculturation and distress, and a range of mental health conditions is contradictory, and limited as applied to psychosis (Koneru *et al.*, 2007). Salant and Lauderdale (2003) have explained that one of the principle reasons for disparate findings is inconsistency in how and what aspects of acculturation are being measured. Certain studies use ethnic specific scales (*e.g* Snowden & Hines, 1999; Landrine & Klonoff 1994; *African American Acculturation Scales*), others use ethnic general scales (*e.g* Stephenson, 2000; *Stephenson Multi-group Acculturation Scale*), many use single variables such as language as proxies for acculturation (*e.g* López *et al.*, 2009). Moreover, uni-dimensional scales predominate in the literature (Koneru *et al.*, 2007; Matsudaira, 2006). Using a new multi-dimensional scale devised for use with individuals of Asian and African Caribbean origin, Bhugra *et al.* (2010) reported that African Caribbean patients were significantly more likely than healthy matched controls to report a loss of traditional cultural values. The finding is interpreted in terms of Marginalisation effects as opposed to biculturalism. The Culture and Identity Schedule (Bhugra *et al.*, 2010) is a mix of 140 qualitative and quantitative questions categorised across 15 sections including attitudes to marriage, religious practices and decisions about family matters, food and entertainment. A case-control comparison with individuals from Asian backgrounds showed no differences in the level of drift from traditional values.

On the one hand, this finding is consistent with the results of a case-control comparison of psychotic and non-psychotic non-Western immigrants in Holland, which used a dichotomised scale of ethnic identity and affiliation (Veling *et al.*, 2010). The researchers of this study reported that lack of identification with one's ethnic group was significantly associated with case status in a logistic regression, even after adjustment for marital status, level of education, unemployment, self-esteem, social support and cannabis use. On the other hand, Gonidakis and colleagues (2013) reported that higher scores on the unidimensional Immigrant Acculturation Scale (Madianos *et al.*, 2008) were correlated with better functioning in first-generation immigrants with a diagnosis of schizophrenia, recruited through inpatient units in Athens. Within this context acculturation was interpreted in terms of advantageous assimilation. Similarly, a study by Reininghaus and colleagues (2010) found that strong identification with ethnic minority group status (less acculturation) was associated with increased risk of schizophrenia within ethnic minority populations. The researchers interpreted the effects observed in their study as mediated by perceptions of disadvantage associated with minority group status.

#### ***Criticisms of the concept of acculturation***

Methodological challenges associated with the acculturation concept, together with reports of inconsistent findings, have led to criticism of acculturation theory as presently espoused. Betancourt and López (1993) recommended that acculturation studies should first define what is meant by culture that is relevant to the behaviour and outcome of study, and that this should be defined in terms of values, beliefs, expectations, norms and cultural practices. Hunt *et al.* (2004) reported on the scarcity of studies providing such definitions of culture. In a review of acculturation studies in Mexican American populations, the researchers found that 8% (6/69) of studies provided a definition of culture, and fewer articulated the attitudinal or behavioural domains assigned to each ethnic group. Furthermore, in a particularly fervent criticism of acculturation approaches the authors of the review argued that within these studies '*culture is understood as a nebulous group of characteristics*

*carried by an ethnic group member' (Hunt et al., 2004, p.977). Ponce and Comer (2003, p.5) similarly claimed that Hispanic culture is 'a myth that serves poets, philosophers and politicians, but is ineffective as a scientific concept.'*

For acculturation research to be effective Hunt and colleagues (2004) proposed that studies require four basic elements: first demonstrable *cultural difference*, at least two clear cultural traditions must be definable to be compared, second *identifiable groups*, differentiable collectives of individuals that share each culture, third *cultural contact*, a situation of immigration or new contact must be occurring between two cultures and *cultural change*, new cultural traits must observably be being adopted by individuals, in addition to existing cultural traits or replacing previous ones. This argument supports Betancourt and Lopez's (1993) suggestion that acculturation studies could be more informative if they ascertained which specific element of culture is related to the target variables or outcomes of interest. Bhui and colleagues (2005) for example selected variables assessing food, friendships, leisure pursuits and clothes to examine cultural integration and its association with mental health outcomes in adolescents sampled from schools in a multi-ethnic community.

#### ***Measurement of context-specific cultural values***

The third approach to examining cultural differences in caregiving addresses these points directly by focusing on ethnic-specific cultural values that might affect the core elements of stress, appraisal and coping models. Knight and Sayegh (2010, p.5) have now suggested, in their presentation of an updated cultural model of caregiving, that '*the time has come to leave behind the expectation that cultures will line up along simple single dimensions like individualism to familism...the familism to individualism spectrum is multidimensional, with both obligation and family solidarity or support being possible subcomponents...the role of cultural values in the model also appears to be more group specific*'. Robinson and Knight (2004) originally hypothesised that increased familism would be associated with a positive effect on burden appraisals in caregiving. However, evidence has failed to support this (Kim et al., 2007; Chun et al., 2007). A subsequent study exploring the factor structure and

psychometric properties of familism measures identified multiple constituent elements including *familial obligations* and *perceived family support* (Losada et al., 2008). Further research involving African American and white family caregivers of patients with dementia found that whilst perceived support may have a distress-reducing influence, conversely perceived duty or demands from family may have negative effects on self-reported mental and physical health in carers (Sayegh & Knight, 2011; Losada et al., 2010).

### **4.3 Ethnicity, impact of care/appraisals of caregiving in psychosis**

#### ***Higher perceived burden of care in white-Western populations?***

Perceived burden or impact of care has been studied in caregivers from different regions and cultures in the UK and elsewhere. In a 20-year review of research on race, ethnicity and cultural issues in caregiving (1980-2000) Dilworth-Anderson and colleagues (2002) systematically assessed empirical evidence, including studies that addressed the commonly quoted finding (e.g. Carrà et al., 2012) that black ethnic minority carers are generally less distressed by comparison to white ethnic majority caregivers (particularly when the index of distress is depression). They found that a lack of control for confounding factors, different sample sizes, sampling procedures and measures contributed to conflicting results. In adjusted analyses with similar methodologies 4/10 studies reported that white carers were more depressed than black African American carers (Farran et al., 1997; Haley et al., 1995, 1996; Miller et al., 1995; Lawton et al., 1992). Notwithstanding issues associated with the cultural validity of assessment measures, ethnic differences in reported burden and distress have been interpreted in terms of variations in resilience (Haley et al. 1995). They have also been explained in terms of different cultural attitudes to caregiving (Chan, 2011; Lawrence et al., 2008; Sethabouppha & Kane, 2005; Guarnaccia & Parra, 1996), different coping styles and available resources (Van Wijngaarden et al., 2003; Magliano et al., 2000), as well as differences in caregiver and recipient characteristics from different ethnic groups.

***Ethnic differences in burden of care in psychosis: findings from international studies***

Regardless of ethnicity or cultural background, across countries, studies report that the proportion of carers meeting clinical thresholds for distress and depression is high (Adewuya *et al.*, 2011; Boydell *et al.*, 2013; Gutiérrez-Maldonado *et al.*, 2005; Igberase *et al.*, 2010; Jenkins & Schumacher, 1999; Kuipers *et al.*, 2006b; Moller *et al.*, 2009; Winefield & Harvey, 1993; Yusuf & Nuhu, 2011). This is even by comparison to general population estimates (Magaña *et al.*, 2007). Some studies have reported that white American caregivers are more likely to report negative consequences and burden from their role than black American caregivers (Rosenfarb *et al.*, 2006a; Pruchno *et al.*, 1997; Stueve *et al.*, 1997; Guarnaccia & Parra, 1996; Horwitz *et al.*, 1995; Pickett *et al.*, 1993). Other analyses have focused on increased positive appraisals of caregiving, acceptance and hope in African American and Hispanic or Latino carers by comparison to Euro-American caregivers (Magaña *et al.*, 2007; Guarnaccia & Parra, 1996; Jenkins, 1988).

***Cultural factors influencing appraisals of caregiving: religious beliefs, value of autonomy, family structure and role expectations***

Lawrence and colleagues (2008) proposed a potential role for ‘traditional’ beliefs about caregiving as natural, expected and virtuous in explaining cultural differences in responses to caregiving, and perceived burden of care. The researchers reported a greater frequency of ‘traditional’ beliefs within black Caribbean and South Asian carers, by comparison to white British carers of individuals with dementia in a small qualitative UK study. In a phenomenological study of Buddhist family caregivers in Thailand, Sethabouppha and Kane (2005) suggested that religious values may underpin ‘traditional’ beliefs about caregiving and resultant distress in carers. Thai Buddhist caregivers in their study believed that caregiving involved suffering, but they also understood the experience to be a noble demonstration of compassion that should be approached with acceptance. Guarnaccia and Parra (1996) further posited a role for ethnic group differences in normative patterns of familial growth and development in determining appraisals of caregiving. They suggested

that different beliefs or values about autonomy and independence held by different ethnic groups influence responses to caring for a mentally ill family member. It has also been suggested by other researchers that people from white Western backgrounds may be less tolerant of a loss of productive, contributory role in their relative than other ethnicities (Carrà *et al.*, 2012b). Ethnic differences in the value of autonomy and independence may also affect how much support carers perceive themselves to have. Suro & Weisman de Mamani (2013) have investigated the relationship between family interdependence and carer burden in a sample of Caucasian, African American and Hispanic caregivers of patients with schizophrenia in Miami. The researchers reported no significant differences across ethnic groups in levels of burden, interdependence or mental health outcomes. However, higher levels of interdependence were associated with lower levels of subjective burden. In China, Chan (2011) has approached the investigation of cultural influences in perceived burden of care by examining Confucian principles. Chan (2011) hypothesised that the strong emphasis on specific roles and formalised relationships in families with Confucian belief systems may influence perceived impact of care. Consistent with this hypothesis, Chien *et al.* (2007) found that social support was the best predictor of perceived caregiver burden in family caregivers in an East Asian sample. Furthermore, caregiver burden was positively correlated with age (Chan *et al.*, 2009, Chien *et al.*, 2007). Although potentially explainable in terms of ailing health in older carers, Chan and colleagues (2009) suggested that because familial responsibilities fall on the 'head of household' in traditional Asian cultures, this may accentuate the psychological and emotional impact of caregiving for particular individuals.

***Ethnic-specific correlates of carer burden: a role for stigma?***

Although levels of reported burden or distress may be comparable across ethnic groups once confounding variables and measurement issues are taken into account (Suro & Weisman de Mamani, 2013; Lloyd *et al.*, 2011), the sources and correlates of negative outcomes may still differ (Lloyd *et al.*, 2013). In addition to beliefs about the virtues of caregiving, the importance of independence, and social role obligations, a number of studies have examined

the relationship between perceived stigma and subjective burden in carers of people with schizophrenia. Magana et al. (2007) reported that perceived stigma was significantly related to depressive symptoms in a sample of Mexican American caregivers of adults with schizophrenia. Similarly using qualitative interviews, Chang and Horrocks (2006) reported a 'strong and pervasive' influence of stigma on subjective burden in Chinese caregivers of people with schizophrenia in Malaysia. Few studies have compared directly levels of perceived stigma associated with schizophrenia in carers from different ethnic groups (Knifton, 2012; Knifton et al., 2010; Wong et al., 2009; Corrigan & Watson, 2007; Gary, 2005). However, it has been suggested from qualitative studies in the literature that ethnic minorities may be acutely sensitive to the stigma associated with a family member having a mental illness (Gary, 2005), and that this is often related to cultural beliefs about mental illness (Lauber & Rössler, 2007; Van Brakel, 2006; Fabrega, 1991). For example, there is evidence from UK studies to suggest that cultural or religious beliefs about causation of illness, as divine retribution, punishment, or spiritual possession, can lead to family shame and blame (Knifton et al. 2012, Knifton et al. 2010, Tabassum et al., 2000). Preoccupation with the need to avoid 'losing face' has in turn been associated with delays in help-seeking, social isolation and increased familial burden (Schomerus & Angermeyer, 2008; Tsang et al., 2003).

***Ethnic-specific correlates of burden: differential interaction with formal support services?***

Evidence suggests that cultural beliefs may influence ideas about causes of illness, which in turn may partially determine perceived utility of interacting with formal medical treatments, and derived benefits from this support (Chan, 2011). Caudle (1993) has noted a tendency in Latin American families to emphasise the importance of expressing needs and feelings. By contrast Tseng and colleagues (1995) described how beliefs about keeping secret something that is unfortunate or degrading to the family name were typical in families in China. These studies of cultural beliefs and speculation on their impact on service-use and perceived burden of care in psychosis have largely been conducted within 'countries of origin'. Within



a UK context, Knifton has noted the need to consider how strongly cultural beliefs that may affect perceived burden in carers are held in 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> generation immigrant communities (*Knifton, 2012*).

Addressing this issue, Lloyd and colleagues (2013) recently reported that subjective burden was associated with use of formal support services in white British carers but not carers identifying as first-generation North Indian Punjabi Sikhs in the UK. The authors suggested that within British Sikh communities caregiving burden may be more likely to be shared with co-resident family members and the wider community. Social networks did not interact with burden in either group in this study. However there were significant differences in the frequency and composition of social networks. In a previous study, the same group reported that Indian patients were more likely to be living with their families than white British patients (*Lloyd et al., 2010*). The researchers posited this as an explanation for the fact that Indian parents were more likely to report burden from psychotic behaviours than British parents in their sample (*Lloyd et al., 2010*). Some studies have suggested that psychotic and disruptive behaviours may predict greater variance in subjective burden within immigrant communities in the US (*Rosenfarb et al., 2006a*) and the UK (*Lloyd et al. 2010*) by comparison to White western carers, although the reasons for this are unclear. Studies from non-Western countries have underscored the importance of enabling families to feel competent in their abilities to cope with problematic behaviours in relatives with psychosis (*Caqueo-Urizar et al., 2012; Aggarwal et al., 2011*). However, it has been reported that provision of information or education alone may be insufficient to alleviate burden, and in the shorter term may even be associated with higher burden (*Sefasi et al., 2007*). In black African and Caribbean families in the UK, researchers have also investigated the potential impact of greater involvement in compulsory detention procedures and compulsory treatment of relatives on perceived burden in carers (*Ghali et al., 2012; Lawlor et al., 2012; Morgan et al., 2005a; Morgan et al., 2005b*). Compulsory detention of patients has been

associated with greater subjective burden (as indexed by perceived problems with services) in carers (Boydell *et al.*, 2013).

National differences in levels of burden reported by carers of individuals with schizophrenia have also been explained in terms of availability and use of formal support services. Controlling for patient illness characteristics, sociodemographic factors and coping abilities in carers, Roick and colleagues (2007) reported that British carers (n=170) were more likely to report feelings of burden than German caregivers (n=333). It was suggested that support for individuals with psychosis may have shifted more towards community care in Britain than in Germany. The importance of regional variation in mental health care provision and coping resources in predicting differences caregiving burden in psychosis has been implied in further European cross-country comparisons (Van Wijngaarden *et al.*, 2003; Magliano *et al.*, 2000). Internationally, it is noted that most countries do not provide financial or institutional support for families with a relative with mental illness and that the responsibility typically rests with family (Adewuya *et al.*, 2011; Aggarwal *et al.*, 2011).

#### **4.4 Cultural differences in attributions and illness beliefs in psychosis**

##### ***Explanatory models of illness in non-western communities***

In addition to influencing appraisals of the caregiving experience, cultural background is also considered to influence attributions about patient behaviours and explanatory models of mental illness (Bhui & Bhugra, 2002). Empirical studies have examined illness beliefs across countries, within patient samples, their relatives, and in the general population (*e.g.* Yang & Wonpat-Borja, 2012; Burns *et al.*, 2011; Broussard *et al.*, 2010; Saravanan *et al.*, 2008; Charles *et al.*, 2007; Conrad *et al.*, 2007; Schnittker *et al.*, 2000). A more limited number of studies have investigated illness beliefs within, and across, different ethnic groups in the UK (Codjoe *et al.*, 2013; Upthegrove *et al.*, 2012; Brown *et al.*, 2011; Borrás *et al.*, 2007; Bhui *et al.*, 2006; Horne *et al.*, 2004; McCabe & Priebe, 2004; Sheikh & Furnham, 2000)

A recent systematic review by Bhikha and colleagues, (2012) examined studies of explanatory models of illness, particularly in psychosis, within non-western countries. The authors noted the important distinction made by Kleinman (1980) between general beliefs about mental illness and explanatory models of illness (for example the self-regulation framework) that guide cognitive and behavioural responses in dealing with a specific episode of illness. This point is relevant when interpreting the results of general population studies of illness beliefs in which reported beliefs are not necessarily related directly to experiences of illness. For example, Compton and colleagues (2008) examined beliefs about the causes of schizophrenia in a non-clinical community sample of 127 African Americans. Responses were given to the diagnostic label 'schizophrenia' rather than to a clinical vignette of symptoms. The four most commonly cited causes were disturbed brain chemistry (50%), drugs and alcohol (43%), hereditary (41%) and avoidance of problems (38%). The most commonly endorsed esoteric causes were possession by evil spirits (28%), radiation (20%) and punishment by god (20%). The researchers noted however that esoteric causes were cited more frequently by individuals who had never known anyone with a diagnosis of schizophrenia.

#### ***Systematic differences in causal attributions***

Bhikha et al.'s (2012) systematic review identified 14 studies conducted across regions of India, China, Africa, Malaysia and the Middle East. Their distillation of findings identified a central focus on *causes* of illness (as opposed to other illness representations including identity, consequences or timeline) and their association with duration of untreated illness, help-seeking and medication adherence. Most studies reported on the preponderance of supernatural or spiritual causes of illness cited by patients and relatives, with varying relative frequencies recorded, by comparison to psychosocial or biomedical explanations (Bhikha et al., 2012). It has been observed that individuals hold multiple and often contradictory beliefs about the origins of illness (Saravanan et al., 2008) and that these are often transient rather than fixed (McCabe & Priebe, 2004). In a large sample of families of

individuals with chronic schizophrenia in India (n=254) Srinivasan & Thara (2001) for example found that 2% of individuals reported exclusively supernatural or spiritual causes as an explanation for illness, all other citations were in combination with psychosocial, personality or biomedical causes. The majority of families held psychosocial explanations as their primary belief model.

***The influence of explanatory models of illness on help-seeking in psychosis***

The research interest in explanatory models of illness in psychosis has often been related to their association with help-seeking and duration of untreated psychosis. A number of studies in non-Western countries have associated supernatural explanations of psychosis with greater and often primary consultation with traditional healers (Abbo, 2011; Burns *et al.*, 2011; Sharifi *et al.*, 2009; Razali & Yasin, 2008; Saravanan *et al.*, 2007; Mbewe *et al.*, 2006). Yet this is not true of all. For example, in a sample of 78 patients with psychosis in India, Chadda *et al.* (2001) reported that 58% went directly to a psychiatrist on first presentation of symptoms versus 30% of individuals who made first contact with alternative healers. Explaining the rationale for their help-seeking choices, individuals in this study cited the ‘trustworthiness’ of traditional healers as a reason for approaching non-medical advisors more frequently than beliefs about the cause of illness. However, it is unclear whether or not treatment by traditional healers in different regions significantly impacts on duration of untreated illness in psychosis (Phang *et al.*, 2010)

***Ethnic variations in pathways to care in the UK: a role for differences in illness beliefs?***

In one of the most recent studies of ethnic variations in pathways to care in the UK, Ghali and colleagues (2013) recorded a longer mean DUP amongst white British patients (n=215) than those who identified with other ethnicities from the UK Census (2001) classifications. In this study of 775 people registered with Early Intervention in psychosis (EIP) services in London, the finding was significant in all white British vs other ethnic group comparisons except for black Caribbean patients. The researchers further reported in adjusted analyses that first generation black patients (of African or Caribbean origin) were five times as likely

as white British patients to have made contact with EI services through criminal justice agencies. Further inspection of the relationships between DUP and care pathways in this study revealed a negative association between DUP and emergency pathways to care, and a positive correlation with initial contact with primary care services. Possible system-related mechanisms resulting in delayed referral from GP services were therefore implicated in explaining the findings (*Ghali et al., 2013*). Although cultural differences in illness beliefs, and in particular aetiology, are frequently implicated in determining help-seeking behaviours and pathways to care, there are only a few UK studies in psychosis samples that explore the association directly (*e.g. Sheikh & Farnham, 2000; Hatfield et al., 1996*). Sheikh and Farnham (2000) reported that gender, religious beliefs and education were predictive of positive attitudes to seeking professional help for mental distress; however culture was not. The difficulty of reducing complex illness narratives into quantifiable variables is highlighted as a barrier to research into the associations between illness beliefs and help-seeking behaviours (*Bhikha et al., 2012*).

***The impact of ethnic differences in explanatory models of illness on treatment satisfaction and adherence in the UK***

Using a semi-structured interview (*Short Explanatory Model Interview, Lloyd et al. 1998*) McCabe and Priebe (2004) examined the relationship between explanatory models of illness in individuals with schizophrenia and satisfaction and adherence with treatment across four ethnic groups. They raised the issue of discord in the explanatory models of illness in patients versus mental health care professionals and the impact that this may have on engagement with treatment. The researchers reported that white patients in their sample were more likely to cite biological causes of illness than those individuals identifying as second-generation immigrants of African-Caribbean or Bangladeshi origin. Moreover, a biological explanatory model was associated with greater treatment satisfaction and stronger therapeutic alliance, but not with treatment adherence. Borrás and colleagues (2007) also explored treatment adherence in a sample of 103 stabilised outpatients with schizophrenia in

Switzerland. However, the researchers examined specifically the influence of religious and spiritual beliefs on representations of illness and treatment adherence, as opposed to ethnicity. They recorded that 57% of patients had a representation of illness that was directly influenced by their spiritual beliefs. In approximately one third of cases this was reflected in positive appraisals of the role of illness in their life, as for example '*part of God's plan and so I accept it with humility.*' (Borras et al., 2007; p.1242). By contrast in approximately one quarter of cases religious beliefs gave meaning to illness with negative contents, including for example '*as a punishment sent by God for my sins.*' The researchers further noted the prominence of religious beliefs in treatment non-adherent and partially adherent individuals, by comparison to those who were fully adherent. Approximately one third of individuals with poorer treatment adherence reported an incompatibility between their religious beliefs and taking medication. This was in comparison to 8% of fully adherent outpatients. However, the greater the importance of religion in the person's life, the less likely they were to report co-morbid substance abuse in this sample. In a stepwise logistic regression, including sociodemographic variables, clinical characteristics and religion, only less positive symptoms and absence of substance abuse were found to predict better treatment adherence.

There are several studies that have employed measurement instruments rooted in Leventhal's self-regulation framework (e.g. the *Brief Illness Perceptions Questionnaire (BIPQ)*, Broadbent, 2006) to compare illness representations of common mental disorders in different ethnic groups in the UK (e.g. Taylor et al., 2013; Brown et al., 2011; Bhui et al., 2006). Overall, the evidence supports the notion that cultural background may influence help-seeking and treatment choices, although consistent patterns have yet to emerge. Taylor and colleagues (2013) examined illness representations in North Indian (n=70) and white British women (n=70) in response to a vignette of a clinical case of depression. The researchers reported that North Indian women were less consistent in their descriptions of the '*identity*' of the difficulties. They perceived fewer emotional consequences of the illness for the individual and believed treatment would be less efficacious than white British

women. North Indian women were also less likely to suggest that the individual should visit a GP. However, no differences were reported in the causes cited for illness between the two groups. In a previous study using the same design methodology, Brown and colleagues (2011) compared the responses of black African women and white British women and reported that black African women were more likely to perceive depression as having less serious consequences, to be less chronic and less amenable to treatment than white British women. They were also significantly more likely to cite social factors as the principal cause of illness than white British women. Bhui and colleagues (2006) compared explanatory models of illness for mental distress in Bangladeshi (n=79), black Caribbean (n=85) and white British (n=97) individuals who reported difficulties in the preceding month. The researchers noted that Bangladeshi and black Caribbean patients were more likely to favour spiritual and medical treatments for common mental disorder than white British individuals, who preferred self-management and social treatments. However, the causes cited for illness did not always predict treatment preferences in this study.

***Ethnic differences in explanatory models of illness in carers of individuals with psychosis***

In one of the only published studies to examine explanatory models of illness in carers as well as patients engaged with EIP services, Upthegrove and colleagues (2012) recorded a strong association between carer and patient appraisals of loss and personal control over illness in a small sample of families from white British, Asian and black African and Caribbean backgrounds. Although it was not discussed explicitly by the authors, this finding raises the issue of concordance in illness representations between carers and patients, as addressed by Kuipers et al. (2007), and its potential influence on the strength of the caregiving relationship. In addition, in this study (Upthegrove et al., 2012), immigrant families might have been expected to hold different models of illness in subsequent generations. Of relevance to this hypothesis, is the counterintuitive finding from Sheikh and Farnham (2000) that younger British Asians were more likely to hold supernatural explanations for their mental distress than older British Asian adults. However, stage of

illness may have confounded these results. Additionally, Bhikha (2011, unpublished) reported a high prevalence of supernatural causes of illness in younger British South Asian patients in a first-episode sample.

It has been suggested that religion may be associated with fewer attributions of controllability to patients (*Rosenfarb et al., 2006a; Alvidrez, 1999*). However, the only known study to measure health locus of control across different ethnic groups in the UK did not report on these differences (*McCabe & Priebe, 2004*). Furthermore, it does not necessarily follow that there would be less blaming attitudes in relatives with different belief systems, although such attributions might influence perceptions about the utility of treatment. Higher internal locus of control in carers has been associated with high EE (*Hooley, 1998*), but not in all studies (*Bentsen et al., 1997*). Weisman and colleagues (2003) examined attributions in a small, low EE sample of Latin American carers of individuals with schizophrenia. They reported from a qualitative analysis that participants were unlikely to hold their relative responsible for their illness. However, on exploring the perceived causes of illness, 90% endorsed biological causes, with a comparative 40% giving at least one reference to God's influence in their causal attributions. This suggests that illness legitimacy, whatever the belief system that underpins this, is the relevant determinant of high EE criticism. The researchers further noted that those with religious beliefs confirmed that religion provided a sense of hope and comfort in 'coming to terms' with their relative's illness (*Weisman et al., 2003*). Religious beliefs were negatively correlated with anger and frustration towards the patient in this study. Weisman and colleagues (2003) suggested that religious coping may predict low EE in Latino families. However, the study design did not permit this to be examined directly.



#### 4.5 Ethnic differences in coping in psychosis

##### *A focus on religious coping: measurement issues*

Examination of cultural differences in coping styles has typically focused on religious coping. Koenig and colleagues (1998, p.513) define this as *'the use of religious beliefs or behaviours to facilitate problem-solving and to prevent or alleviate the negative emotional consequences of stressful life circumstances'*. In a meta-analysis of quantitative studies of religious coping and psychological adjustment to stress, Ano & Vasconcelles (2005) differentiated between methodologies that investigated dispositional religious coping versus situation-specific religious coping. The meta-analysis focused on the latter. The reason cited for this approach was that empirical studies examining the relationship between single-item measures of religious affiliation, frequency of church attendance or importance of religious belief (*e.g Murray-Swank et al., 2006*) might attest to the significance of religion in predicting responses to stress, however they reveal little about the specific intrinsic or 'intrapsychic' religious processes that people employ in relation to a particular event. This is consistent with Pargament and colleagues (2000, p.521) argument that *'it is not enough to know that an individual prays, attends church, or watches religious television. Measures of religious coping should specify how the individual is making use of religion to understand and deal with stressors'*.

In a review of the psychology of religion and coping, Pargament, (1997, p.32) defined religion as *'a search for significance related to the sacred'*. In a follow-up to this, Harrison and colleagues (2001) explained that religious coping should be conceptualised as a multi-dimensional construct involving active and passive processes, both problem-focused and emotion-focused, positive and negative. The researchers specified five strategies or mechanisms that have underpinned the construction of the majority of popular scales of religious coping (*e.g RCOPE, Pargament et al., 2011, 2000*): spiritual support/discontent, congregational support/discontent, benevolent/punishing reframing, orientation to agency

or control; and the use of rituals. Three orientations to agency or control have generated the most interest (Pargament *et al.*, 1988): ‘self-directing’, ‘deferring’ and ‘collaborative.’

### ***Religious coping and distress***

It is reported that religious coping contributes unique variance to psychological outcomes following a negative event, including quality of life (QoL) and levels of mental distress (Utsey *et al.*, 2007; Harrison *et al.*, 2001; Pargament 2000). In a sample of 385 African Americans from ‘high risk’ urban communities, Utsey and colleagues (2007) examined the relationships between perceived QoL, spiritual and collective coping, and ‘traditional’ resilience factors including cognitive ability, social support and familial factors. Using structural equation modelling they reported a significant relationship between religious coping and QoL above and beyond traditional predictive coping factors. Consistent with this empirical finding, Pargament and colleagues (1998, p.710) have argued that ‘*religious coping cannot be reduced to non-religious coping*’. Nevertheless, Park (2005) has emphasised the association between religious coping and ‘meaning making’ coping. In a sample of bereaved college students, Park (2005) recorded an association between religious coping and subjective well-being, that was mediated by positive reappraisal coping. Finding meaning, including through religious belief, has been reported elsewhere to mediate the relationship between appraisals of carer burden and emotional distress in carers of individuals with dementia (McLennon *et al.*, 2011). Harrington (2011) therefore suggests that other coping styles and mechanisms may ‘overlap’ with religious coping in addition to positive re-appraisal.

### ***Positive and negative religious coping in psychosis***

Investigations of religious coping in psychosis caregiving populations are limited. In a longitudinal study of 48 young adults with a diagnosis of schizophrenia or bipolar disorder Phillips and Stein (2007) reported that positive religious coping, including benevolent religious reappraisals of illness, were predictive of positive subjective wellbeing over the course of one year. By contrast, negative reappraisals of illness, in terms of God’s

punishment or reappraisals of God's power (in which God's control or power is questioned as a result of illness), were associated with self-reported distress and loss. Rabinowitz and colleagues (2010) have also made the distinction between negative and positive religious coping styles. They examined their associations with cumulative health risk in Latina and Caucasian carers of individuals with dementia. The researchers reported that valence of religious coping style respectively predicted increased and decreased cumulative health risk. Controlling for age, race and gender, Murray-Swank and colleagues (2006) found that religious coping (as measured by importance of religious beliefs and receipt of religious support) correlated with less depression, better self-esteem and better self-care in a sample of 83 carers of individuals with a mental illness. Similarly, Herrera et al. (2009) reported that positive religious coping was associated with lower perceived burden in Mexican American caregivers, whereas negative religious coping (e.g. feeling that carer burden is a punishment) was associated with higher self-reported depressive symptoms.

#### ***Religious coping and Expressed Emotion***

In the only known study to examine religious coping and its relationship to Expressed Emotion directly, Wasserman and colleagues (2013) used a modified version of the COPE scale (Carver *et al.*, 1989) to assess 'adaptive' and 'maladaptive' non-religious coping (NRC) and the Religious Coping Activities scale (Pargament *et al.*, 1990) to assess 'adaptive' and 'maladaptive' religious coping (RC) in a sample of 72 family members of individuals with schizophrenia. The researchers hypothesised that religious coping would predict EE over and above non-religious coping. In step-wise regression analyses 'adaptive' NRC (e.g. positive reinterpretation, growth and acceptance) predicted low EE, however 'maladaptive' NRC (e.g. venting emotions, behavioural and mental disengagement, denial) did not predict high EE. Overall, religious coping was found to predict EE status independently of secular coping. However, neither the positive RC subscale (e.g. accepting the limits of personal control, seeking and accepting guidance, negotiating and bargaining with a Higher Power and diverting attention from a negative event to living a more religious

life) nor the negative RC subscale (e.g distance from one's religious community, and doubt about one's religious belief) predicted EE. This is consistent with results from Rammohan and colleagues (2002) who found that the strength of general religious belief, but not religious coping, was associated with psychological wellbeing in carers of relatives with schizophrenia in India. The authors suggested that '*the cognitive aspect, i.e. belief in God, takes precedence over the behavioural domain of specific religious practice*' (Rammohan et al., 2002, p.361).

#### 4.6 Cultural specificity of Expressed Emotion

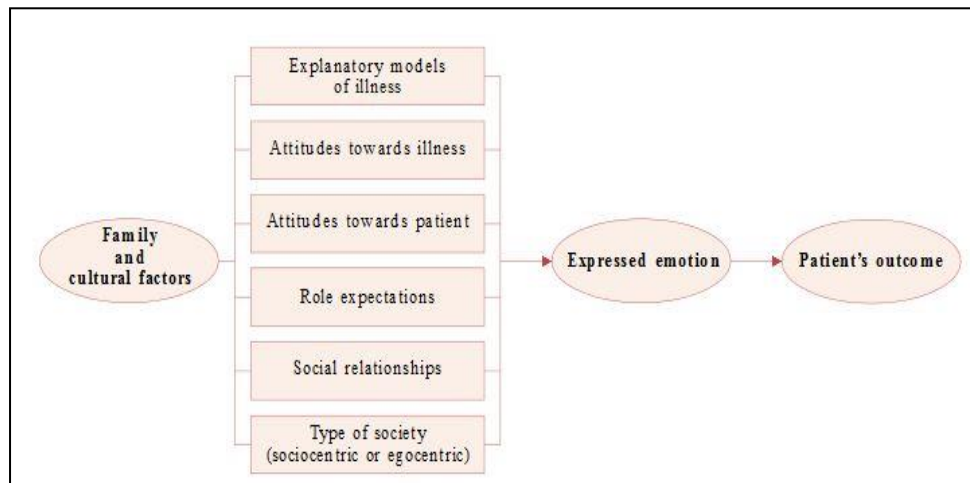
##### *A cultural conceptualisation of EE behaviours*

Work by Jenkins at the University of California, Los Angeles, is widely cited for its seminal contribution to thinking about the cross-cultural validity and specificity of the Expressed Emotion concept (Jenkins & Karno, 1992; Jenkins, 1991). In an anthropological analysis of Expressed Emotion Jenkins and Karno (1992, p. 9) proposed that EE could be conceptualised as '*family response to an ill relative*' and that culture defines what kinds of behaviours are '*transgressive*' and therefore likely to elicit critical or intrusive responses in carers. Referencing methodologically comparable studies of EE in non-Western countries available at the time, they substantiated their argument with reports of differential rates of high EE, and varying prevalence of the indices of EE, in Indian and Mexican-American samples by comparison to European and North American samples (Karno et al., 1987; Leff et al., 1987; Wig et al., 1987a,b; Jenkins et al., 1986; Vaughn et al., 1984; Vaughn & Leff, 1976b; Brown et al., 1972). Jenkins had suggested in an earlier paper (1991) that from an anthropological perspective EE-criticism could be conceived of as negative responses to '*perceived cultural rule violations*' and emotional overinvolvement as reactions to '*a behavioural transgression of perceived boundaries*.' This suggests in some ways a more limited theoretical espousal of Expressed Emotion than Hooley and Gotlib's (2000) dynamic systems approach, or more recent cognitive models (Kuipers et al., 2010b). However,

Jenkins and Karno (1992) did not intend their definitions it to be exhaustive. The researchers further acknowledged in their paper that *‘other theoretical accounts are also necessary. Relatives’ responses to a family member’s illness include a complex of features that dynamically interact with one another.’* (Jenkins & Karno, 1992, p. 16). In an abbreviated outline, Jenkins and Karno (1992) went on to propose a potential role for culture in influencing, for example, interpretations of the nature of illness, the meanings of kin relations, identification of cultural role violations and family interactive dynamics. A decade later, in a review of Expressed Emotion across cultures, Bhugra & McKenzie, (2003) provided a visual representation that encapsulated many of these points (**Figure 5, overleaf**). Their conceptualisation is consistent with Rosenfarb’s (2006b) sociocultural stress-appraisal coping model of carer burden (**shown in Figure 4, p.77**).

Empirical research into the cross-cultural validity of the EE construct and its measurement has typically encompassed, first, those studies that have examined within-group rates of EE and its indices in other countries, and compared these with rates from US and UK samples. Secondly, studies have compared the profiles of EE indices across different ethnic groups, in the UK and elsewhere. In some cases this has also included analyses of associations with acculturation. Thirdly, studies have examined the predictive validity of EE across countries, to verify its association with patient outcomes and specifically with relapse. Fourthly, there have been investigations into the concurrent validity of EE that have explored its associations with for example self-reported carer burden in different ethnic groups. Finally, a small number of studies have attempted to take a more ethnographic approach and have examined the evidence for attitudinal and behavioural signs of EE, whilst also observing different patterns of social interaction in families caring for someone with psychosis in non-Western cultures. Please see **Table 2, Appendix 1**, for details of these studies conducted over the last 25 years that have examined the cultural validity of EE.

**Figure 5: Family and cultural characteristics that may influence patient outcome through expressed emotion**



*Bhugra and MacKenzie, (2003); p.347*

***Within ethnic-group variation in rates of high EE and its indices across countries***

Differences in the ratios of high to low EE in families from different countries have been noted since the early development studies in Expressed Emotion. In controlled comparisons Wig and colleagues (1987b) reported significantly lower proportions of high-EE responses in families caring for someone with schizophrenia in Chandigarh, India (23% of 78) by comparison to Aarhus Denmark (54% of 28) or London, UK (54% of 46). Furthermore, by dividing the larger Chandigarh sample into rural and urban dwellers the researchers noted that proportions of high EE amongst rural families was 8% by comparison to 30% for those living in the city. Leff and colleagues (1987) subsequently suggested that familial responses to illness may account for the prognostic differences for schizophrenia reported in developing countries by the WHO studies at the time (*Jablensky et al., 1992*). In an overview of studies comparing western and non-western rates of high EE, Lefley (1998) proposed that it was ‘*primarily among urban families of Anglo-Saxon cultural heritage that the number of high EE relatives exceeded low-EE families*’ (Lefley, 1998, p.99).

Since then studies using a translated version of the CFI in Nigeria for example (*Ewhrudjakpor, 2009; Reicher et al., 2003*) have noted higher rates of high-EE in families

caring for psychosis patients (63-80%) than those quoted in reviews of European countries (Kuipers, 1992; mean = 55% from 11 studies) or internationally (Kavanagh, 1992; median = 54% from 24 studies). Ewbrudjahpor (2009) used a cut-off criteria of >20 critical comments in obtaining these rates in Nigeria. In a study of 32 Pakistani relatives of patients with schizophrenia, Ikram et al. (2011) reported that 75% of families were high EE using the CFI, with 54% of these rated so on the basis of emotional overinvolvement. By contrast, Ran et al. (2003) found similarly low rates of high EE (28%) to those obtained in the Chandigarh study within families caring for someone with psychosis in Chengdhu, China. Ran and colleagues (2003) also acknowledged a tendency for urban dwellers to be more emotionally expressive in their study than those from rural areas.

However, speculating on the meaning of comparative differences in proportions of high EE reported in single studies against means or medians from elsewhere (*e.g in Singh et al., 2013*) should be done with caution. Even in studies using similar methodologies, differences in the sample characteristics make direct comparisons problematic. Furthermore, within country variation in rates across studies is observed in aggregate analyses (Kavanagh et al., 1992).

#### ***Comparisons of EE profiles across ethnic groups***

A series of studies have examined differences in rates of EE and its indices in controlled comparisons across different ethnic groups. Nomura and colleagues (2005) reported low levels of high EE in Japanese carers of individuals with dementia (5% of 20) or schizophrenia (30% of 20) by comparison to UK carers of individuals with dementia (40% of 20) or schizophrenia (55% of 20). The group further noted large differences in the number of critical comments across the groups, with 2 being the median number of critical comments for Japanese carers of people with schizophrenia, compared to a median of 6.5 critical comments for UK carers of individuals with schizophrenia.

Pooling the data from 5 studies of Mexican American and Anglo American samples (*López et al., 2009; Dorian et al., 2008; Kopelowicz et al., 2006; Karno et al., 1987; Vaughn et al. 1984*), Lopez and colleagues (2009) reported that Anglo Americans (24% of 224 patients and carers) were significantly more likely than Mexican Americans (76% of 224 patients and carers) to be rated as high EE using the CFI (67% versus 37%). They further noted that Anglo Americans reported significantly higher levels of criticism, less warmth and less EOI than Mexican Americans in adjusted analyses. US acculturation (measured on the basis of greater English language use and Western media preferences) in Mexican American carers was also associated with higher levels of criticism ( $p < .05$ ). Previous support for the finding that Latino/Hispanic carers of patients with schizophrenia have lower rates of high EE (15% of 21) than white American carers (47% of 20) was reported by Weisman de Mamani et al. (2007). However, similar comparisons of EE using an alternative interview to the CFI, with White and Hispanic families of adolescents with eating disorders, have however reported few if any differences on the key EE scales (*Hoste et al., 2012; Hoste & le Grange, 2008*).

Within the UK, ethnic group comparisons in rates of high EE have focused on British Asian populations. Hashemi & Cochrane (1999, 1997) examined Expressed Emotion in 60 families caring for someone with psychosis who self-identified as British Sikh, British Pakistani or white British in terms of ethnicity. They recorded rates of high EE as 30% (of 20), 80% (of 20), and 45% (of 20) in these groups respectively and reported that EOI was found significantly more frequently in Pakistani families than British Sikhs. Comparisons in levels of EE between white carers and British Pakistani carers, and white carers and British Sikhs were non-significant. However, Hashemi and Cochrane (1999) highlighted that the modal score for EOI was 4 in Pakistani families as opposed to 1 for white and Sikh carers. This is consistent with the rates of high EOI observed in studies conducted in Pakistan (*Ikram et al., 2011*). The authors suggested that high emotional overinvolvement may represent a cultural norm in this ethnic group in Britain. By contrast, in a slightly smaller sample of carers who identified as first-generation North Indian Punjabi Sikhs in Britain ( $n=23$ ) or white British



(n=16), Lloyd and colleagues (2013) rated 56% of Sikh families as high EE based on their attitudes and behaviours versus 19% of white British carers. As opposed to Hashemi and Cochrane (1999) they reported a large proportion of EOI ratings within the high EE category in British Sikhs (69% of 13 high EE dyads). This study also examined cross-sectionally the relationship between levels of self-reported burden and EE in carers. However, the correlation was non-significant. Similar to Hashemi and Cochrane (1999), the authors argued that EOI behaviours may be normative in certain cultures, but in this case for British Sikhs. They suggested that this may explain the lack of association between high EE and carer burden in their sample. A forthcoming qualitative study by Lloyd and Burns supports this interpretation (Lloyd *et al.*, 2013, p. 154).

***Cross-cultural variation in the predictive and convergent validity of the EE indices***

More broadly, the cultural specificity of EOI behaviours has been considered in a recent systematic review by Singh and colleagues (2013). The researchers identified 28 longitudinal studies from the literature that reported on the validity of EOI in predicting clinical outcomes in patients across different cultures or countries. The authors concluded that the relationship between high EOI and poor outcomes was inconsistent across cultures. Within European samples they recorded that 5/8 studies found no relationship between EOI and outcomes in families caring for someone with psychosis in Swiss-French, Dutch, Italian and German samples (Barrelet *et al.*, 1990, Lenior *et al.*, 2002, Lenoir *et al.*, 1998, Stricker *et al.*, 1997; Montero *et al.*, 1992). Similarly, the majority, (Marom *et al.*, 2002, 2005; Ng *et al.*, 2001; Leff *et al.*, 1990, 1987), although not all studies (Tanaka *et al.*, 1995) conducted in Asia reported no association between EOI and clinical outcomes.

However, it has been suggested that high EOI and low warmth may be stronger predictors of relapse and symptom change within Mexican American samples than criticism (Aguilera *et al.*, 2010). High EE (mostly rated on the basis of EOI) was associated with relapse over 12 months in a study of Mexican Americans by Kopelowicz and colleagues (2006). Both Lopez *et al.* (2004) and an earlier study by Kopelowicz *et al.* (2002) found that the criticism

dimension of EE was predictive of relapse in Anglo Americans and Caucasian families but not in Mexican American families. Similarly, in a reanalysis of data from 44 Mexican American carers and patients (*Karno et al., 1987*), Breitborde and colleagues (2007) reported that criticism did not predict relapse over 9 months. However, EOI and warmth did. Moreover, by conducting a quadratic rather than linear regression between EOI and clinical outcomes they demonstrated that the relationship was best modelled by a J-shaped curve. Breitborde et al. (2007) have suggested that high warmth may act as a ‘buffer’ against moderate levels of EOI. This is consistent with studies conducted in Italy and Serbia (*Ivanović et al., 1994; Bertrando et al., 1992*), in which warmth was independently associated with clinical outcomes.

Yet confirmations of the prospective association between overall high EE and relapse (*Roseliza-Murni et al., 2013*), and of cross-sectional correlations between overall high EE and carer burden (*Carrà et al., 2012b; Chan et al., 2010*), continue to be reported in large samples in newly-researched regions. Given the extent of the evidence recording higher rates of psychosis in black African and Caribbean populations in the UK compared to the white British population, Jadhav (2009, p.94) comments that ‘*it is indeed surprising that there is not a single study examining the role of Expressed Emotions amongst the British Black population.*’. This is an interesting observation because within African American samples, there are a handful of studies that question the reliability of high EE in predicting relapse (*Kymalainen & Weisman de Mamani, 2008*). In a small, mixed Caucasian and black sample (66% of 24) Moline and colleagues (1985) reported that within the black subgroup of carers a significant correlation between high EE and relapse was not observed at any cut-off point for criticism. In a comparison of the predictive validity of EE ratings derived from the Five Minute Speech Sample (*FMSS, Magaña et al., 1986*) and scores on a measure of perceived criticism in patients, Thompson et al. (1985) similarly found no relationship between high FMSS-EOI or high FMSS-criticism at baseline and psychotic exacerbation at 1 year follow-up in African American families. However, they note that patient perceived criticism

predicted outcomes in this group 87% of the time. This suggests there is an issue with the measurement of EE criticism from relatives. Over 12 months, all of the individuals rating high perceived criticism (PC) at baseline showed a significant increase in symptoms by contrast to 31% in the low PC group.

Using a 10-minute problem solving task with carers and patients to measure EE attitudes and behaviours at baseline, and monitoring illness course over 2 years, Rosenfarb and colleagues (2006a, 2004) recorded that high levels of relatives' critical and intrusive behaviour were associated with better clinical outcomes in their sample of black African American families. This was in contrast to results obtained for white Caucasian American families. Interpreting these findings, the authors referenced studies of racial differences in styles of conflict resolution (Davidson, 2001) and the levels of affect present in normative verbal communication styles across ethnic groups (Rogan & Hammer, 1998). They suggested that African American service users may experience critical and intrusive behaviour as a symbol of engagement, caring and support (Rosenfarb et al., 2006a). Providing further support for this collection of findings, Weisman and colleagues (2006) reported that CFI-derived criticism was not associated with patient perceived criticism in a cross-sectional analysis with a small sample of African American families. This may suggest, that in some families, raters are not allowing for culturally appropriate expressions of concern.

#### ***Understanding cultural variation in measurements of EE***

This point is made by other authors. Reflecting on early differences in the levels of EOI reported in caregiving relationships in schizophrenia (Jenkins & Karno, 1986) and their inconsistent association with patient outcomes, Kuipers (1992, p.432) noted that *'it is not clear from the data available to what extent EOI varies across cultures. If it does vary, is this due to natural and potentially interesting aspects of different cultures or to variation in the so far subjective rater decisions about 'unusual responses' to mental illness in different cultures? Investigation of this would require that ratings were formalised and examples of extreme ratings discussed and agreed on when a new language is being investigated.'*

Further authors have also questioned the meaning of observed cultural differences in EE profiles in families. Lopez and colleagues (2009, p.2) surmised that *'cross-ethnic and cross-national differences may not necessarily reflect 'cultural' differences in Expressed Emotion, but instead may reflect, at least in part, an artefact of applying an instrument that inadequately measures the given construct in a new cultural context.'*

Singh et al. (2013) additionally drew attention to methodological differences in studies of EE and relapse across cultures and the ways in which variation in the measurement instruments and operationalised definitions of relapse complicated interpretation of results. Contending with these issues in practice is problematic and individual research teams have proposed different approaches. Bhugra and MacKenzie (2003, p.343) advise that *'if measures of Expressed Emotion are being applied in cultures where they have not been used before they must be accompanied by fieldwork to establish the norms of the context.'* Yet within the extensive number of studies noted above and in **Appendix 1, p. 276** there are few instances in which heeding this advice has been done. Subandi et al. (2011) is one example of a study, albeit on a small scale, in which ethnographic interviews, akin to Brown's early empirical observations, have been attempted with Javanese families of patients with schizophrenia.

#### ***Contending with cultural variation in measurements of EE***

Singh and colleagues (2013) noted two alternative methods by which researchers have attempted to investigate, and improve, the predictive utility of the EE dimensions in different ethnic groups. First, a number of studies have made post hoc adjustments to individual scales to improve the predictive utility of overall EE, or individual scales. For example, Hashemi (1997) reported that raising the EOI 'cut-off' score to 4 for British Pakistani and British Sikh groups, enabled global EE to predict relapse, when no association was reported for the standard score of 3. However, as noted above (Bebbington & Kuipers, 1994) this risks reporting relationships of spurious significance. By contrast, a few studies have attempted to make a priori adjustments to the types of attitudes and behaviours rated as

evidence for the dimensions of EE. For example, Jenkins and Karno (1992), and using the same data, Breitborde (2007), identified behaviours within Mexican-American familial interactions that they considered to typify high EOI, including somatic complaints in carers specifically related to their relative's illness, which they termed '*nervios*', or expressions of suicidal thoughts in carers described as resulting from their relative's illness. However, this complicates the process of drawing comparisons across studies (Kuipers, 1992).

The importance of verifying the validity and predictive utility of EE across ethnic groups and non-Western cultures is best demonstrated within the context of interventions in psychosis. Whilst Jadhav's (2009, p.95) criticism that '*clinical work that reduces Expressed Emotions is simply dangerous outside Euro-American families unless locally validated*' may overstate the issue for those living in the UK, it is generally agreed that family interventions need to consider sociocultural differences in identifying the aspects of relationship functioning that are causing stress to patients and caregivers (Singh et al., 2013; Bhugra & McKenzie, 2003). In an alternative to the methods described above, Aguilera and colleagues (2010, p.14) have suggested that '*this would call for the development of a clinical assessment tool that can identify the emotional climate(s) and sources of conflict that should be targeted based on what is most stressful and damaging to the patient.*' This view is supported by studies such as Tompson et al.'s (1995, p. 155), the results of which led the authors to suggest that '*when family environments are examined in patients of ethnic minority groups, the patient's perspective may be a more potent predictor of outcome than traditional measures of EE.*' This suggests strongly that a direct measure of patient experiences of family relationships might now be a better predictor of outcomes across cultures.

## **Chapter 5: Measuring the quality of caregiving relationships**

### **5.1 The patient's perspective**

The role and perspective of the patient within familial interpersonal interactions has attracted research attention at least since the 1970s (*Scott, 1973*). Studies have been variously motivated to understand the dynamic interactions in caregiving dyads and triads (*Scott et al., 1993*), to identify a pathway by which external stressors, including Expressed Emotion, may impact on vulnerable individuals with a variety of conditions (*e.g Scazufca et al., 2001*), as predicted by the new cognitive models of psychosis (*Garety et al., 2001*), and to generate shorter alternatives to the Camberwell Family interview for assessing the quality of caregiving relationships, with research and clinical applications (*Hooley & Parker, 2006*).

Despite earlier studies (*Cole & Kazarian, 1988; Warner & Atkinson, 1988*), Hooley and Teasdale's (1989) examination of the differential utility of Expressed Emotion, perceived spousal criticism (PC) and marital satisfaction to predict relapse in depressed patients has gained significant recognition for advancing research in the area (*Renshaw, 2008*). Using a single item (Perceived Criticism Measure, PCM), rated on a 10-point scale that asked '*how critical do you think your spouse has been of you in the last month*', they reported that PC accounted for greater variance in relapse rates in depression over a period of nine months than Expressed Emotion and marital distress combined. Each of the variables was independently associated with increased relapse. However, PC alone predicted approximately 38% of the total variance in patients' outcomes and the addition of further variables to a hierarchical regression model did not significantly add to the predictive power. Furthermore, PC ratings were not significantly correlated with clinical assessments of symptomatology in their sample at baseline; moderate to good test-retest reliability was measured for the item across the same period ( $r(18) = .06, p < .01$ ). Correlation analyses showed that PC was moderately associated with overall EE levels ( $r = .51, p < .02$ ; high versus low). However, it did not correlate significantly with the CFI-derived criticism scale. Acknowledging the limitations of the study, and the unanswered question of why perceived

criticism should be so closely aligned with relapse, the researchers speculated that PC ratings may provide a measure of how much criticism is '*getting through to the patient*' (Hooley & Teasdale 1989, p.234). This they explain may in part reflect how critical their relative is objectively, but may also be a function of the sensitivity of the patient to criticism.

Since then a number of studies have specifically explored the predictive utility of perceived criticism, based on the ease with which it can be measured, and the extensive evidence base supporting the role of criticism as the principal predictive component of Expressed Emotion (See Table 3, p. 184). In a review of prospective studies conducted in patient populations with depression, anxiety, bipolar disorder, substance abuse and schizophrenia, Renshaw (2008) reported that higher rates of PC were predictive of worse psychological outcomes in seven out of twelve studies, and unrelated to psychological outcomes in four studies. The use of variable measures was highlighted as a complicating factor in the assessment of studies and Renshaw therefore focused specifically on applications of Hooley and Teasdale's (1989) PCM item. By contrast Lebell *et al.* (1993) examined symptom exacerbation over 12 months in a sample of schizophrenic outpatients and its relationship to ratings on a 5-point Likert measure of the extent to which patient's judged their relative to hold '*strong negative thoughts and feelings*' about them. As has been noted elsewhere, in relation to alternative items generated to examine patient perceptions of Expressed Emotion (Cutting *et al.*, 2006), this may require greater theory of mind from patients than reporting directly on perceived criticism. Furthermore, responses to this question may be more likely to be confounded by illness characteristics, such as poor concentration or working memory. More recent studies examine perceived '*negative attitude of others*' (NAO) as a prodromal symptom related to beliefs about others intentions towards oneself (Salokangas *et al.*, 2012). Perceived NAO in this sense is conceived of as '*distorted interpretations of relationships that may be located at the core of psychotic experience*' (Salokangas *et al.*, 2009, p.234). Renshaw however identified a majority of studies in which scores on the PCM were neither correlated with demographic and psychopathological variables (*e.g* Kwon *et al.*, 2006;

*Miklowitz et al., 2005*), nor were entirely confounded by measures of relationship quality (*Fals-Stewart et al., 2001; Riso et al., 1996*). The review surmised, from the then present evidence, that PC demonstrated strong discriminant validity. However, it was reported that ‘support for the convergent validity of the PCM as a measure of the actual level of criticism directed toward a respondent is more equivocal’ (*Renshaw 2008; p.530*).

This issue of convergent validity is particularly relevant within psychosis research as there is considerable debate as to the ability of affected individuals to perceive and process emotions in general (*Tremeau, 2006*). Meta-analyses suggest that individuals with schizophrenia may be impaired in emotion recognition and processing by comparison to controls across multiple sensory channels, including facial expressions (*Chan et al., 2010; Kohler et al., 2010*) and affective prosody (*Hoekert et al., 2007; Shea et al., 2007; Edwards et al., 2002*). It is also suggested that vulnerable individuals may be particularly sensitive to differential processing of unpleasant or negative emotional content by comparison to controls (*Li et al., 2010; Bellack et al., 1992*). Nevertheless, following pioneering research (*Lebell et al., 1993; Thompson et al., 1995; Scazufca et al., 2001*) a number of studies now support the utility of patient perceptions of expressed emotion outcomes in predicting psychopathological outcomes.

## **5.2 Predictive and convergent validity of perceived criticism in psychosis**

For example, using a detailed family interview to assess patient perceptions of family dynamics developed for the study, *Tompson et al. (1985)* extracted ratings of perceived criticism, nagging and emotional overinvolvement from the responses of 81 patients with schizophrenia and the relative with whom they had most contact. Patient perceived criticism was found to predict significant symptom exacerbation on the Brief Psychiatric Ratings Scale (*Lukoff et al., 1986*) at 12-month follow up. Moreover, PC was correlated with criticism measured objectively using the Five Minute Speech Sample (*Magana, 1986*), in all



Caucasian families, but not those from ethnic minority backgrounds. PC did not correlate with symptoms at baseline.

Further studies, conducted in related patient samples, have looked at the predictive utility of perceived criticism as measured by the PCM. For example, Schlosser and colleagues (2010) reported in a sample of individuals At Risk of psychosis that both perceived criticism and CFI-derived criticism were predictive of an increase in prodromal symptoms over 6 months; with PC predicting 21% of the variance in positive symptoms at follow-up. In order to differentiate perceptual processing of criticism from potential biases inherent in illness, the researchers assessed whether PC was related to suspicious thinking, as measured by the Structured Interview for Psychosis Risk symptoms at baseline (*Miller et al., 2002*), and found no association. However, PCM scores were unrelated to CFI ratings of criticism or warmth in this sample when tested using Pearson's correlations. Schlosser and colleagues (2010) also included an adapted measure of perceived warmth, based on the same format as the PCM. Although the specific items were not quoted, perceived warmth was significantly negatively correlated with criticism ratings from the CFI and positively correlated with warmth ratings from the CFI. Yet, perceived warmth scores did not contribute to the prediction of symptom changes at follow-up.

Contributing to the debate as to why perceived criticism may be related to relapse, Miklowitz and colleagues (2005) found that the extent to which patients with bipolar disorder were upset by perceived criticism, rather than scores on the PCM, was predictive of change in mood symptoms and days in recovery after 12 months. A different approach was however adopted in selecting the significant other person to take part in the study. Participants were asked to select up to three relatives who were involved in their healthcare and with whom they had greater than 4 hours per week face-to-face contact. To capture best the strongest effect on mood symptoms the individual with the highest attributable perceived criticism score was included in the analyses, as opposed to the individual with whom the patient had the most contact. The study nevertheless suggested that psychosocial

interventions in psychosis may benefit from addressing the level of emotional distress patients experience in response to negative evaluations from significant others. The researchers also recommended controlled cross-sectional studies of the association between perceived criticism and established measures of EE to advance the debate on the validity of PC as a self-report instrument for use in clinical practice.

Four studies to date support the convergent validity of the PCM (*Hooley & Teasdale, 1989*) in psychosis samples. First, using the item with an adapted Likert response format, Scazufca et al. (2001) reported moderate associations between PC and both the CFI criticism and hostility subscales at inclusion. This association was weaker at follow-up. The distribution of responses was unrelated to levels of positive or negative symptoms at baseline; and in further support of the relative accuracy of patient perceptions of criticism despite variations in mental state, responses were fairly consistent in test-retest reliability analyses conducted over 9 months. Second, Cutting et al. (2006) also reported modest associations between PC, CFI criticism and overall EE ( $r=.39$ ,  $p<.05$ ;  $r=.44$ ,  $p<.01$  respectively) in a small sample of outpatients with schizophrenia. Four items designed to measure perceived emotional over-involvement were trialled in this study. However, these were not significantly correlated with emotional over-involvement as measured by the CFI. The main findings of the study were that self-reported sensitivity to criticism was not associated with perceptions of criticism from influential others, but was associated with the degree of stress patients reported from face-to-face interactions with influential others. The results are interpreted as further support for the EE as stressor hypothesis in which critical attitudes expressed in interview with an objective-rater are assumed to translate into interpersonal interactions in face-to-face encounters between patients and carers at home. Third, Weisman et al. (2006) recorded a moderate cross-sectional association between perceived criticism and CFI ratings of criticism in 47 white Caucasian and Latino patient-carer dyads; this was not however replicated in a sub-sample of black African American families. Most recently, Onwumere and colleagues (2009) reported moderate correlations between patient-reported and

interviewer-rated measures of criticism. In hierarchical regression analyses, this relationship remained significant even after controlling for mood disturbances, negative affect and general psychopathology in patients.

### **5.3 Measuring perceived Expressed Emotion in psychosis**

Evidence has grown in support of the utility of measuring patient perceptions of criticism in psychosis, and of the validity of the single-item Perceived Criticism Measure (*PCM*, Hooley & Teasdale, 1989). However, self-report instruments are less consistently validated that assess patient perceptions of the other indices of Expressed Emotion (*Bachmann et al., 2006; Hooley & Parker, 2006; Van Humbeeck et al., 2002*).

The Level of Expressed Emotion Scale (*LEE*, Cole & Kazarian, 1988) is a sixty-item, true/false response scale that can be used to measure the patient's perspective of emotional interactions with family members. A Relative Version also exists that enables a self-report evaluation of the caregiving relationship. Items were generated by Cole and Kazarian (1988) to constitute four subscales, of 15 items each; respectively measuring perceived intrusiveness, emotional response, negative attitude towards illness and tolerance and expectations from relatives. The dimensions were theoretically rooted in qualitative criteria outlined by Leff & Vaughn (1981) that observably differentiated high EE from low EE families. Total scores on the Patient version of the LEE were recorded to correlate  $r=.32$  (n.s) with the number of criticisms made by carers of individuals with schizophrenia during the Camberwell Family Interview (*Kazarian et al., 1990*). Significant correlations were reported between CFI criticism and patient scores on the intrusiveness and tolerance/expectations subscales ( $r=.40$ ,  $p<.05$ ). Cole and Kazarian demonstrated that patient LEE scores were independent of age, gender and contact hours (*Cole & Kazarian, 1988*) and provided provisional evidence for the ability of total LEE scores, dichotomised based on a median split, to predict rehospitalisation in a sample of individuals with schizophrenia, at 1, 2 and 5 years after initial assessment (*Cole & Kazarian, 1993*). Donat (1996) confirmed this finding in a large sample of individuals discharged from a public psychiatric hospital

with varied clinical diagnoses; and noted that in addition to total LEE score, only the intrusiveness subscale demonstrated predictive value. Comparing the results of further validation work on the LEE is limited by alterations and adaptations that have been made to the scale by different groups of researchers. Gerlsma and colleagues (1992) translated the scale into Dutch and altered the response format to a 4-point Likert scale. Based on a principal components analysis of scores on the 60-item scale, they questioned the intended four-factor structure and proposed a 33-item scale comprising three dimensions assessing Lack of Emotional Support ( $\alpha = .89$ ), Intrusiveness/control ( $\alpha = .78$ ), and Irritability ( $\alpha = .79$ ). However, along with Startup (1999), the researchers noted the absence of items directly measuring perceived criticism in a confirmatory factor analysis of the three-factor shortened scale. These were added by Gerlsma and Hale (1997) who found that the newly added 5-item Criticism scale was more predictive of clinical outcome in a sample of depressed individuals and their partners than total LEE score or any of the other subscales ( $r = -.53$  and  $r = -.64$  for change scores in the Beck Depression Inventory, *Beck et al., 1961*; and the Symptom Checklist 90 respectively, *Derogatis et al., 1974*). Those who perceived their spouses as more critical were less likely to show improvement in depressive symptoms over a period of 6 months. Further studies have variously applied the 60-item version translated into Italian (*Di Paola et al., 2010*) and the shortened 38-item version (*Moulds et al., 2000*) within samples of individuals with eating disorders with mixed results as to the concurrent and predictive utility. There is ongoing debate as to the factor structure of the 38-item scale administered within adolescent samples (*Nelis et al., 2011; Hale et al., 2007*) and a 50-item version translated into Chinese has also been proposed (*Chien & Chan, 2010*).

Partially motivated by a perceived specificity of the original LEE to schizophrenia samples, and concerns about the length of the scale, Shields and colleagues (1992) developed the Family Emotional Involvement and Criticism Scale (FEICS) as an alternative assessment of the patient's experience of critical and overinvolved interactions. The researchers generated 14 items that were intended to be analogous to the criticism and EOI dimensions of the CFI

interview. However, in construction of their Emotional Involvement scale they noted a departure from the '*implied negative evaluative judgement about behaviour*' (Shields *et al.*, 1992, p. 397) presumed to be inherent to the EOI index of Expressed Emotion. The EI subscale therefore includes items such as '*My family knows how I am feeling most of the time.*' Although the construct validity has been assessed in relation to other indicators of family cohesion, adaptability and interpersonal support (Shields *et al.*, 1994), as well as the PCM (Bachmann *et al.*, 2006), no known studies examine correlations with the CFI or the ability of subscale scores to predict clinical outcomes in different conditions. There are no indications as to potential cut-off scores (Van Humbeeck *et al.*, 2002). Good internal consistency is reported for the scales and the criticism subscale has been correlated  $r=.57$ ;  $p<.01$  with the PCM (Nelis *et al.*, 2006; Bachmann *et al.*, 2006). However, as with the LEE Scale, debate has continued as to the factor structure of the FEICS in different samples (Nelis *et al.*, 2006; Gavazzi *et al.*, 2003), possibly explaining why Shields and colleagues went on to focus on applications of the criticism scale alone (Fiscella & Campbell, 1999; Fiscella *et al.*, 1997).

More recently Medina-Pradas and colleagues (2011) have collated the Brief Dyadic Scale of Perceived Expressed Emotion (BDSEE) incorporating 14 items in the patient version. Four items assess perceived criticism; six items (extended from Cutting *et al.*, 2006) are intended to assess emotional overinvolvement and three items assess perceived warmth. The intended factor structure of the scale was confirmed in a sample of 77 patients with eating disorders and their key relatives (an individual involved in their healthcare with whom they have the greatest amount of contact). Using principal components analysis (varimax rotation) the items loaded on three factors. Correlations were computed between the subscales and the FEICS (Shields *et al.*, 1992); the Parental Bonding Instrument (Parker *et al.*, 1979); the Inventory for Assessing Memories of Parental Rearing Behaviour (Perris *et al.*, 1980) and the Authoritative Parenting Measure (Steinberg *et al.*, 1992). Convergent validity with the CFI was also assessed in the same group with the BDSEE criticism subscale correlated

modestly with criticisms made in the CFI ( $r=.31$ ,  $p<.01$ ) and with EOI ratings from the CFI ( $r=.26$ ,  $p<.05$ ) and with overall EE classification ( $r=.40$ ,  $p<.001$ ). The BDSEE EOI subscale also correlated with all CFI indices:  $r=.37$ ,  $p<.01$ , with EOI;  $r=.31$ ,  $p<.01$ , with criticism;  $r=-.24$  with warmth and  $r=.44$ ,  $p<.001$  for overall EE. The warmth items in the BDSEE subscale only correlated with high versus low EE categorisation ( $r=-.27$ ,  $p<.05$ ). Improved levels of internal consistency ( $\alpha$ 's  $=.82$  to  $.92$ ) were reported by comparisons to the original reported on the BDSEE, submitted for publication (*Keefe et al., personal communication*).

### **Literature Review Summary**

Carers support the recovery of individuals in poor health and are increasingly relied upon by society to meet healthcare needs. Scientific scrutiny of caregiving relationships has demonstrated that this can be at a cost to their own wellbeing. Understanding the extent of the impact of caregiving on health, and identifying predictors of its magnitude, is therefore a priority for governments worldwide to enable scarce finance to be invested in targeted support measures for those in greatest need. Whilst Census data in the UK has begun to document the extent of caregiving activity, there are few studies that investigate carer health at a national level. Moreover, care-recipient characteristics are rarely captured such that the impact of caring for someone with mental health issues can be compared with other carers. There is some evidence to suggest that this may result in higher perceived burden. The first of three studies in this thesis (**Chapter 6, p. 121**) therefore aims to investigate impact of care on physical and mental health, in carers in general, in a national survey sample. The remaining studies focus on carers of individuals with psychosis specifically.

Psychosis is a complex psychiatric condition that takes a high toll on individuals, families and society, yet it remains poorly understood by comparison to other mental health issues. The contribution that a sociocultural approach has made to advancing our understanding of the phenomenology, epidemiology and aetiology of disorder is highlighted at every juncture. Differences in symptom expression and clinical presentation across cultures have influenced conceptualisation of disorder. Higher reported incidence rates in migrants globally, and in black African and Caribbean individuals in the UK in particular, implicate social and environmental risk factors and suggest pathways for prevention. Biological, psychological and sociological perspectives on causation all posit a prominent role for sociocultural schema in influencing cognitive and emotional processes that determine the development and persistence of positive symptoms in psychosis.

Families and caregivers are often responsible for initiating contact with medical services when a relative experiences a first-episode of psychosis. They can also help to provide and support an environment conducive to recovery. A cognitive model of caregiving in psychosis has contributed to our understanding of family interactions and their potential impact on carer and service-user health. The research that supports this conceptualisation also underpins the structure, content and delivery of Family Interventions (FI) in psychosis. Recently questions have been posed as to whether this model and FI require adaptation to incorporate cultural differences in caregiving processes. The importance of this research is highlighted against a backdrop of documented inequalities in access to and routes to mental health services for ethnic minorities, and their reported reduced satisfaction with psychological care.

The empirical construct Expressed Emotion (EE) has provided a framework for understanding the dynamics of interpersonal interactions and a means by which to measure the quality of caregiving relationships, reliably, validly and over time. It has also provided a focus for models which seek to understand caregiving within the context of patient recovery and carer health. The composite indices have been shown consistently to predict relapse in patients in the shorter term, and both physiological and psychological mechanisms have been evidenced by which high EE may impact on individuals with psychosis. These include by influencing levels of stress and arousal and altering mood states and self appraisals.

Certain cognitive processes are thought to contribute to the development of behaviours and patterns of communication that typify high EE. Firstly, negative appraisals of caregiving, and carer 'burden' predict high EE. Evidence suggests that a sizeable proportion of carers may experience complex grief reactions and trauma in supporting a relative with psychosis. Secondly, attributions made about patient behaviours, together with wider beliefs about the causes and consequences of illness are related to distress in carers and their responses to patients, and thirdly, at a time when they are acutely needed, carers may lose touch with vital social support systems due to stress and perceived stigma.



Bringing the evidence together, a cognitive model of caregiving clarifies not only the processes that are associated with distress and difficulties but also those that lead to the maintenance of positive responses to caregiving. A central role has emerged for coping styles as a target for interventions, with proactive coping and positive reappraisal, as opposed to avoidance, influencing adaptive responses in carers.

To ensure responsive clinical services, an evidence base is therefore required on potential systematic differences in appraisals of caregiving, explanatory models of illness and coping styles in communities of different ethnicities. Notwithstanding the complexities of defining and measuring culture, a number of studies support the premise that sociocultural background influences responses to caregiving and resultant carer distress levels. In the UK, research suggests that not only are individuals of black African or Caribbean origin (BA\_BAC) at greater risk of developing psychosis than other ethnicities, but also that BA\_BAC carers are more likely to be engaged in crisis situations involving the police and emergency services in navigating pathways to care for their relative. Moreover, they are more likely to experience, and to have to play a part in, the compulsory admission and detention of a vulnerable family member. The second study in **Chapter 7, p. 140**, therefore aims to investigate differences in cognitive and emotional processes reported by carers of individuals who have experienced a recent first-episode of psychosis and who self-identify their white British or black British, African or Caribbean origins. Given the questions raised in the literature about the cross cultural validity of the EE construct, the final study in **Chapter 8, p. 180**, examines the concurrent validity and factor structure of a short scale of perceived Expressed Emotion. It has been suggested that a measure assessing interpersonal dynamics from the patient's perspective may be of particular use within families of non-Western backgrounds.

## **Chapter 6: Study 1: mental and physical illness in caregivers\***

### **6.1 Study 1: Aims and hypotheses**

The first study investigated the relationship between the number of hours spent caregiving per week (as an objective measure of burden) and psychiatric and physical morbidity, based on an English national sample (*the 2007 Adult Psychiatric Morbidity Survey: APMS 2007*). The primary hypothesis for the study was that carers reporting higher caregiving demands (in average hours per week) would report poorer mental and physical health than non caregivers (*Legg et al., 2013*). The study was designed to test the null hypothesis that there is no linear relationship between hours per week spent caregiving and the mental and physical health of caregivers, assessed by self-report and standardised clinical interview, when appropriately controlling for other confounding factors. The APMS 2007 employed a stratified, random probability sampling method to provide robust weighted data representative of the English adult population aged 16 and over. This also allowed new estimates for the frequency of caregiving in the general population to be compared with recent national estimates.

### **6.2 The Adult Psychiatric Morbidity Survey**

Primary outcome measures were obtained from the Adult Psychiatric Morbidity Survey (APMS) 2007 (*McManus et al., 2007*). The third in a series of national surveys commissioned by the NHS Information Centre for health and social care and conducted by the National Centre for Social Research (NatCen) in association with the University of Leicester. Previous surveys in the series were completed in 1993 and 2000. The APMS series is the principle source of data on treated and untreated psychiatric conditions in adults aged 16 and over living in private households in England. It includes assessment of common mental disorders as well as more severe psychiatric conditions.

\* a version of this study is in press with the *BJP*, Appendix 8

### **6.3 Methodology**

#### ***Sampling procedure***

Interviews were conducted between October 2006 and December 2007. Private households were identified via the small user Postcode Address File (PAF). The small user PAF consists of all Royal Mail delivery points receiving fewer than 50 items of mail each day. It provides a comprehensive database of private households in England. The proportion of households living at addresses not on the PAF is estimated at less than 1%. The primary sampling units were individual or grouped postcode sectors, which were stratified by regional area and markers of socio-economic status. Delivery points were randomly selected within each postcode sector, based on probabilities calculated in proportion to size (the number of delivery points). Site visits yielded 13171 eligible addresses for inclusion, and one person over the age of 16 was selected from each identified household using the Kish grid method (*Kish, 1949*). A total of 7,304 people (57% of those potentially eligible, and 70% of those successfully contacted) completed Stage 1 interviews with trained representatives from NatCen Social Research. Stage 1 assessed socio-demographics; general health, common mental disorders and service use, and included a self-administered section for certain psychiatric conditions. A sub-sample of respondents consented to a Stage 2 clinical interview, based on Stage 1 screening questions. Ethical approval for the APMS 2007 was granted by the National Research Ethics Service.

#### ***Identifying caregivers***

Caring responsibilities were assessed by computer assisted face-to-face interview. Individuals were asked whether or not they '*look after, or give help or support to family members, friends, neighbours or others because they have a long term physical or mental ill-health or disability, or problems related to age?*' This definition is consistent with comparative surveys (Survey of Carers in Households, 2009/2010; National Census, 2001; General Households Survey, 2000) in avoiding use of the term 'carer' and in specifying long-term as opposed to temporary illness. Participants were also asked to exclude anything

which constituted paid employment. Respondents estimated hours spent caregiving per week (hpw) on a 9 point categorical scale (hours per week: 0-4, 5-9, 10-19, 20-34, 35-49, 50-90, >100, <10 but varies, >10 but varies). Travel time associated with caregiving tasks was included within these estimates.

#### ***Clinical Interview Schedule – Revised (CIS-R)***

The CIS-R is a standardised clinical interview developed for administration by lay interviewers (*Lewis et al., 1992*). It comprises 14 sub sections; each assessing psychiatric symptoms relating to specific diagnostic areas, such as somatic symptoms, generalised anxiety and social phobia. Filter questions establish the presence or absence of particular reference symptoms within the last month. Further questions assess frequency, severity and duration, and time since onset, to enable a 0-4 score to be derived for each symptom area (0-5 for depressive ideas) and a total symptom score of 0-57. The accepted clinical threshold for psychiatric morbidity is >12 (*Bebbington et al., 2000*) and a fourfold categorisation, in addition to overall score, was used for analyses within the present study (0-6, 7-11, 12-17, 18+). A computer algorithm was used to derive ICD-10 diagnoses, based on symptoms present in the last week. Prevalence rates of disorder are presented across 6 combined categories for this study: Mixed Anxiety and Depression (all those scoring >12 but not allocated to a specific ICD-10 category), General Anxiety Disorder, Depression, Phobia, Obsessive Compulsive Disorder and Panic.

#### ***Medical Outcomes Study Short Form Health Survey (SF-12)***

The SF-12 is a self-report questionnaire assessing perceived general health and wellbeing. It represents a subset of items from the SF-36. The original scale has demonstrated reliability, validity and sensitivity in discriminating changes across patient groups (*McHorney et al., 1994; Hays et al., 1993*). Correlations between the SF-12 and SF-36 have been reported at  $r>0.94$  and the shortened scale has been cross-validated across countries and age groups (*Gandek et al., 1998; Ware et al., 1998*). Items in the SF-12 form 8 health domains that are in turn used to calculate aggregate scores for physical and mental health, with higher scores

indicating perceptions of better health (*Wilson et al., 2000; McHorney et al., 1993*). Norm-based scoring was employed, using US population norms, which have demonstrated applicability to UK populations and normative data from the UK is over 20 years old (*Burholt & Nash, 2011; Jenkinson, 1999*).

### ***Chronic physical conditions***

Individuals endorsed the presence or absence of a series of 21 chronic physical conditions in the preceding year. The APMS uses a show card to ensure comprehensive coverage of physical conditions that people may not otherwise think to mention (e.g. problems with skin or hearing). The list comprised cancer, diabetes, epilepsy, migraine, cataracts/eyesight problems, hearing difficulties, stroke, heart attack, high blood pressure, bronchitis, asthma, allergy, ulcers, liver problems, bowel/colon problems, bladder problems, arthritis, bone, back or joint problems, infectious disease and skin problems. The card additionally includes a clause stipulating that the condition must have been present in adulthood and diagnosed by a health professional.

## **6.4 Statistical Design**

The ‘Survey’ commands in STATA 10 for Windows were used as they provide robust estimates of variance in complex data-sets. Weights were calculated to provide a representative sample of the household population over 16 years of age, taking into account differential non-response between regions and age-by-sex groups. Population control data was obtained from the Office of National Statistics 2006 mid-year population estimates. In the present study actual counts are presented, together with weighted means and proportions and 95% confidence intervals as estimates of variance. To reduce standard error, the categories denoting hours spent caregiving per week (hpw) were combined to form five groups for descriptive and inferential statistical analyses (0-9, 10-19, 20-24, 35-99, >100hpw). This was further reduced to three groups (non-caregivers, 0-19hpw and  $\geq 20$  hpw) when comparing proportions of people meeting clinical thresholds for psychiatric

symptoms, due to low numbers at higher symptom levels. Group differences in putative confounding factors identified from the existing literature were assessed with uncorrected Chi-squared and design-based ANOVA tests (age, sex, ethnicity, employment status, marital status, social support, smoking status, daily alcohol consumption, and body mass index). Single linear regression analyses were first conducted to verify the relationship between these factors and physical and mental health outcome variables. Ordinal and categorical predictors were converted into 'Dummy coded' variables using the STATA 'xi' function. Inspection of histograms and the Shapiro-Wilks test were used to assess the normality of the distribution of outcome variables and of residuals in regression models. Multiple linear regression analyses were conducted to examine the relationship between caregiving hours and health outcomes, taking into account confounding predictors. Potential collinearity of independent variables was assessed by inspecting variance inflation factors for each variable. Unstandardised co-efficients are quoted in regression statistics.

## **6.5 Results**

### ***Frequency of caregiving***

Twenty five percent (n=1,883) of participants identified themselves as regular caregivers, of whom nearly all (n=1,874) gave an indication of the number of hours per week (hpw) engaged in caregiving activities. Twenty percent of individuals were engaged in lower amounts of caregiving (0-19hpw) and 4.4% (weighted) reported providing caregiving support for between 20 and over 100 hours per week. Participants who did not quantify time spent caregiving (n=9) and those who indicated that their hours varied (>10 hrs) on a weekly basis (n=46) were excluded from analyses (**Table 4, overleaf**).

Women were significantly more likely than men to identify themselves as caregivers ( $\chi^2 = 10.3$ ,  $df=1$ ,  $p<0.01$ ) and to be engaged in higher levels of caregiving activities ( $\chi^2 = 28.7$ ,  $df = 5$ ,  $p<.0005$ ). Individuals providing greater amounts of care were more likely to

**Table 4: Frequency of caregiving and demographic analyses by number of hours spent caregiving, APMS 2007**

Weighted percentages given for all proportion estimates	Non-caregivers	Caregivers (total)	Sig.	Caregivers grouped by hours per week spent caregiving					Sig.
				0-9 hpw	10-19 hpw	20-34 hpw	35-99 hpw	≥ 100 hpw	
<b>Frequency</b>	75.1	24.9		17.1	2.9	1.4	1.6	1.4	
Unweighted count	5,520/7,403	1,883/7,403		1288/7,348	216/7,348	110/7,348	114/7,348	100/7,348	
<b>Age, mean</b>	45.3	49.5	<b>p&lt;.0001</b>	48.7	48.4	49.4	51.7	55.6	<b>p&lt;.0001</b>
<b>Gender</b> (% Female )	50.3	54.6	<b>p&lt;.01</b>	51.3	58.9	62.7	65.6	64.2	<b>p&lt;.0005</b>
<b>Ethnicity:</b> % in 4 categories: (White, Black, South Asian, Mixed/other) *	89.5 /3.0 /4.2 /3.4	92.4 /3.1 /2.9 /1.5	<b>p&lt;.001</b>	92.3 /3.1 /3.1 /1.5	95.1 /4 /3.2 /1.3	92.3 /2.8 /2.9 /2.0	95.1/2.5 /2.4 /0.0	84.0 /11.5 /0.6 /3.9	<b>p&lt;.005</b>
<b>Marital Status</b> Married/cohabiting	61.0	68.4	<b>p&lt;.0001</b>	68.3	61.2	64.9	72.4	79.1	<b>p&lt;.0001</b>
Single/Separated/Divorced/Widowed	39.0	31.6		31.7	38.9	35.1	27.6	20.9	
<b>No. individuals in household</b> 1	16.7	12.0	<b>p&lt;.0001</b>	13.4	14.4	12.2	5.1	2.5	<b>p&lt;.0001</b>
2	36.8	46.1		44.6	39.9	50.0	51.0	57.8	
≥3	46.5	41.9		42.0	45.7	37.8	43.9	39.7	
<b>Employment</b> Manager/professional	29.7	26.4	<b>p=.05</b>	29.9	26.8	21.1	8.2	10.8	<b>p&lt;.0001</b>
Intermediate	7.3	6.5		6.9	6.4	6.6	2.2	5.0	
Office/Manual	31.7	33.2		34.8	33.7	36.4	36.4	14.5	
Never worked/not worked in last year	31.3	33.9		28.4	33.1	36.0	53.2	69.7	
<b>Current smoker</b>	22.9	23.8	n.s	23.6	23.7	25.9	25.6	23.4	n.s
<b>Alcohol, std drinks per day</b> 0	17.7	16.4	<b>p&lt;.05</b>	13.8	19.9	11.3	22.4	30.0	<b>p&lt;.005</b>
1-4	62.6	65.9		68.1	60.7	70.1	59.0	58.6	
5-6	10.6	10.7		10.8	13.9	13.5	9.3	5.7	
≥7	9.1	7.0		7.3	5.6	4.5	9.4	5.8	
<b>Mean Body mass index</b> (bmi)	25.9	26.5	<b>p&lt;.005</b>	26.3	25.9	27.4	27.5	27.7	<b>p&lt;.01</b>
<b>Mean no. close contacts (Social support)</b>	13.0	13.6	<b>p&lt;.05</b>	13.7	12.6	14.3	14.1	13.5	n.s

\* summed cell percentages do not add up to 100% due to missing data or individuals unable to specify ethnicity

be older ( $F(5, 256) = 14.0, p < .0001$ ). In addition, caregivers were more likely to be married or cohabiting ( $\chi^2 = 31.9, df = 1, p < .0001$ ) and to be unemployed or not to have worked in the last year ( $\chi^2 = 9.9, df = 3, p = .05$ ). Chi squared tests of the proportions of caregivers from different ethnicities engaged in caregiving roles neither indicated the direction of effects nor took into account expected frequencies based on the demography of England. However, markedly more ethnic minority carers, and in particular Black carers, endorsed their involvement in the highest amount of caregiving ( $> 100$  hpw) relative to percentage frequencies of ethnic minorities engaged in lower amounts of care.

There were no significant differences reported in smoking status between caregivers and non-caregivers, nor were there any significant differences in the levels of social support reported by caregivers grouped in five, by hours per week spent caregiving. Body Mass Index was observed to increase marginally, but significantly, in association with increased caregiving hours ( $F(5, 256) = 3.3, p < .01$ ). Additionally, there was a significant overall difference in alcohol consumption across the caregiving groups ( $\chi^2 = 44.9, df = 15, p < .005$ ), with the proportion of teetotal individuals being higher at higher levels of caregiving.

### ***Measures of mental and physical health***

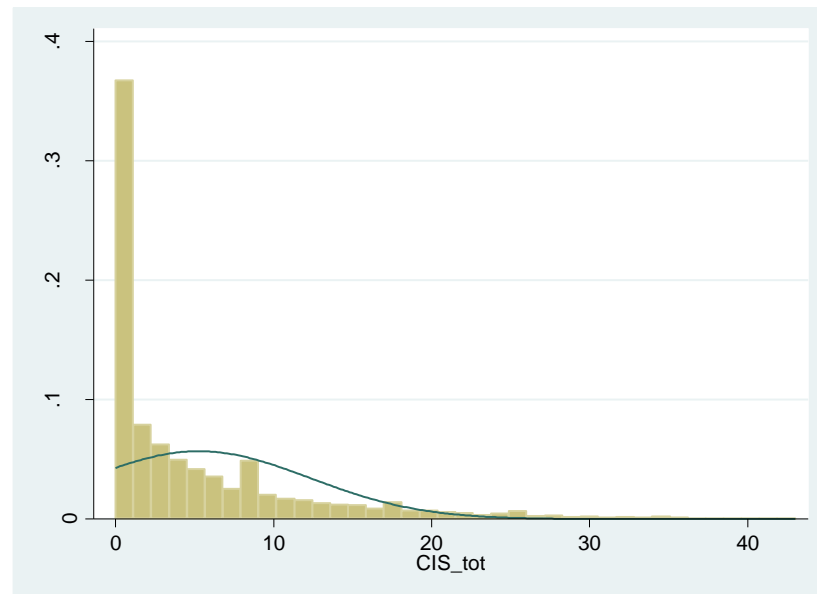
Perceived mental health (SF-12 mental component summary, MCS) was significantly correlated with total scores on the Clinical Interview Schedule – Revised (CIS-R), ( $r = -.54, p < .0001$ ). Likewise, perceived physical health (SF-12 physical component summary scores, PCS) was significantly correlated with the number of diagnosed physical conditions reported by individuals in the preceding year ( $r = -.47, p < .0001$ ).

### ***Mental health: total psychiatric symptom scores and self-reported mental health***

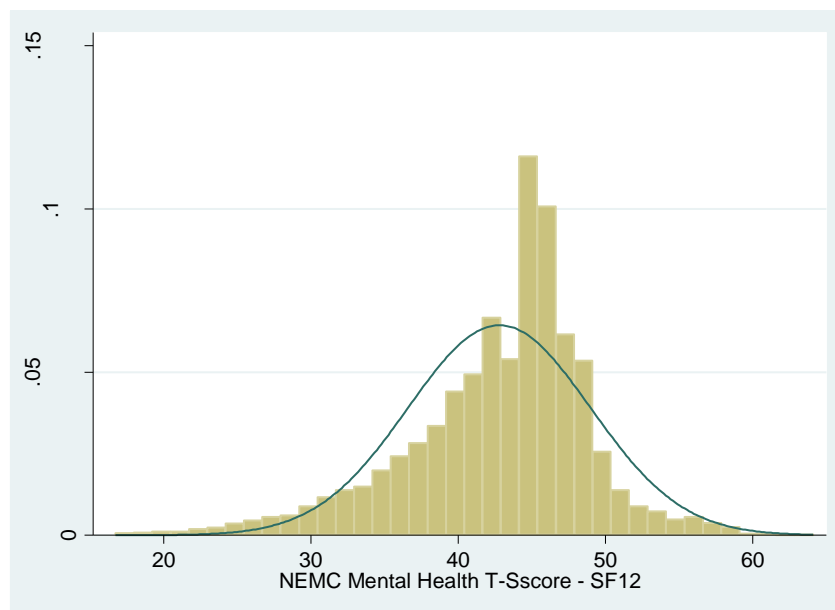
The distribution of outcome scores for total psychiatric symptoms (CIS-R) and for perceived mental health (SF12, MCS) were inspected from histograms (**Figures 6 and 7, overleaf**). A higher frequency of zero values was observed for CIS-R scores (Shapiro Wilks,  $Z = 17.01, p < .0001$ ).



**Figure 6: Distribution of total psychiatric symptom scores (CIS-R)**



**Figure 7: Distribution of perceived mental health scores (SF-12, MCS)**



In an unadjusted linear regression model carers had significantly higher total scores on the CIS-R than non-caregivers ( $F(5, 256) = 16.04, p < .0001$ , **Table 5, overleaf**). In addition, a dose effect was observable for the amount of caregiving. The relationship accounted for 1.6% of the overall variance in CIS-R scores ( $R^2 = .016$ ).

**Table 5: Mean CIS-R score by amount of caregiving (unadjusted)**

Amount of caregiving (hours per week)	CIS-R total score, weighted	Unstandardised co-efficient (B)	95% CI for co-efficient	t-statistic	Significance
<b>Non-caregivers</b>	4.7				
<b>0-9</b>	5.6	.91	(0.47, 1.37)	4.03	<b>p&lt;.0001</b>
<b>10-19</b>	7.9	3.2	(1.99, 4.46)	5.13	<b>p&lt;.0001</b>
<b>20-34</b>	8.2	3.5	(1.75, 5.18)	3.99	<b>p&lt;.0001</b>
<b>35-99</b>	7.2	2.5	(1.09, 3.80)	3.56	<b>p&lt;.0001</b>
<b>≥ 100</b>	8.6	3.9	(2.11, 5.61)	4.36	<b>p&lt;.0001</b>

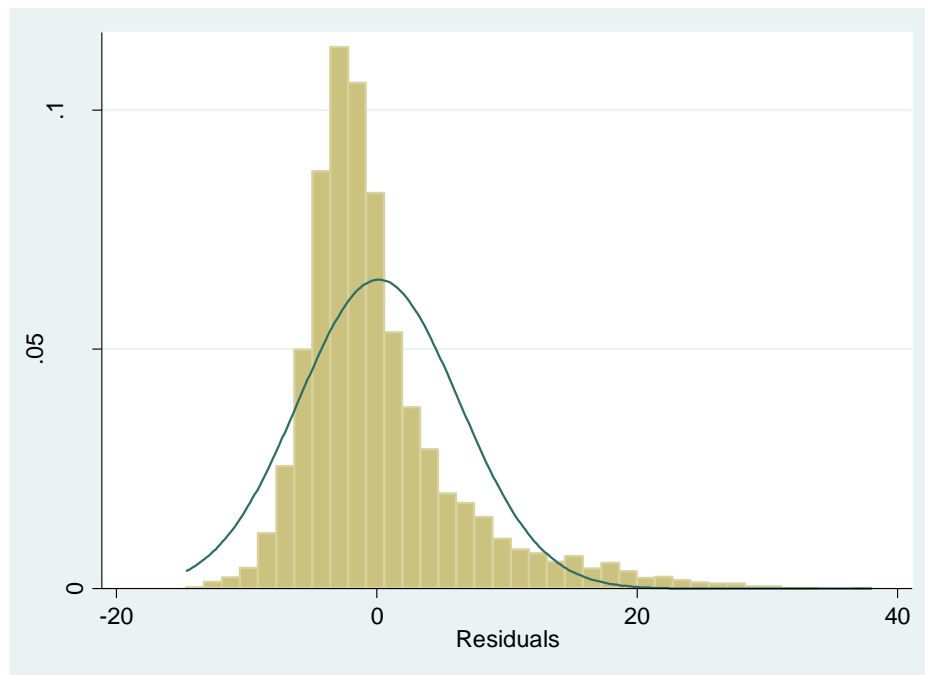
After adjustment for relevant confounding factors in multivariate regression (physical health summary score, age, sex, ethnicity, employment status, marital status, social support, daily alcohol consumption, and body mass index), this relationship remained significant ( $F(18, 243) = 54.47, p<.0001$ ), with minimal variation in the pattern of unstandardised coefficients (**Table 6**).

**Table 6: Mean CIS-R score by amount of caregiving (adjusted)**

Amount of caregiving (hours per week)	CIS-R total score, weighted	Unstandardised co-efficient (B)	95% CI for co-efficient	t-statistic	Significance
<b>Non-caregivers</b>	4.7				
<b>0-9</b>	5.6	1.3	(0.90, 1.77)	5.94	<b>p&lt;.0001</b>
<b>10-19</b>	7.9	3.1	(1.97, 4.13)	5.56	<b>p&lt;.0001</b>
<b>20-34</b>	8.2	2.9	(1.47, 4.38)	3.95	<b>p&lt;.0001</b>
<b>35-99</b>	7.3	2.7	(1.49, 3.99)	4.32	<b>p&lt;.0001</b>
<b>≥ 100</b>	8.8	4.0	(2.30, 5.78)	4.57	<b>p&lt;.0001</b>

The model accounted for 19% of the variance in CIS-R scores ( $R^2 = .19$ ) and tests conducted indicated that multicollinearity was not a concern. Variance inflation factors for all predictor variables were  $< 2.0$ . **Figure 8 (overleaf)** displays the distribution of residuals in the final model. The survey functions in STATA provide robust estimates of standard errors, adjusting for modest skewness and unequal variances.

**Figure 8:** Plot of residuals from adjusted regression of CIS-R total symptom scores



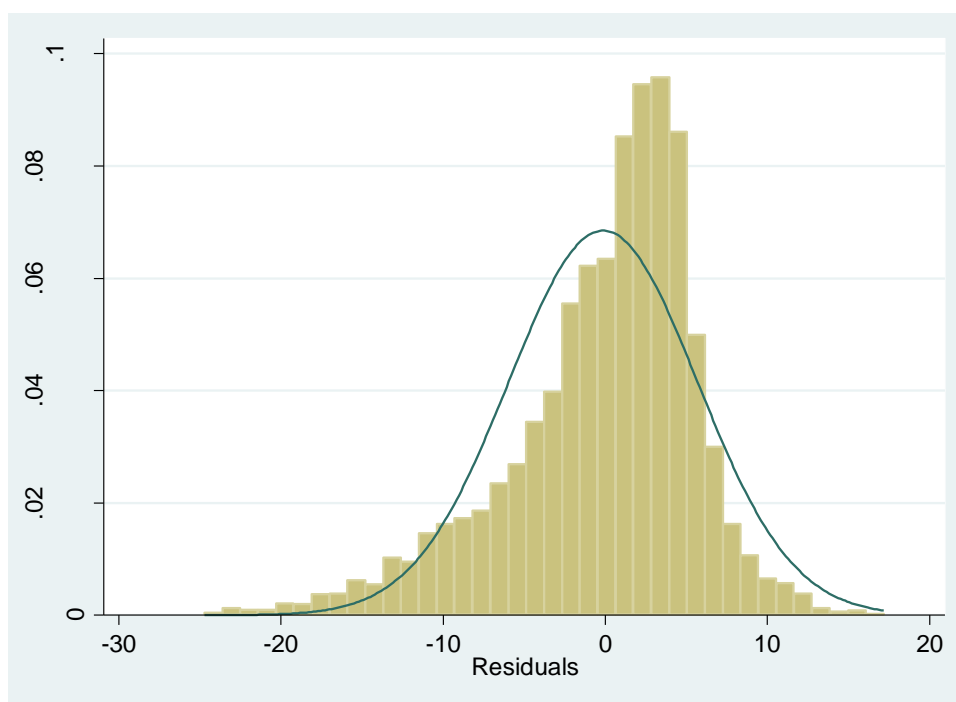
Results for perceived mental health (SF-12 MCS scores) were consistent with CIS-R derived measures of psychiatric morbidity (**Table 7, overleaf**). The overall adjusted multiple regression model was significant ( $F(20, 241) = 25.52, p < .0001$ ) and accounted for 10% of the variance in self-reported mental health scores ( $R^2 = .10$ ). A histogram of the residuals for the model is shown in **Figure 9 (overleaf)**.

Plotting unweighted mean scores on the CIS-R and SF-12 across caregiving categories (**Figure 10, p. X**) indicated a progressive rate of decline in mental health beyond 10 hours per week of caregiving. However, on both measures there is a suggestion that people in the second highest category of amount of caregiving (35-99 hpw) have better mental health than those in the category immediately below (25-34 hpw).

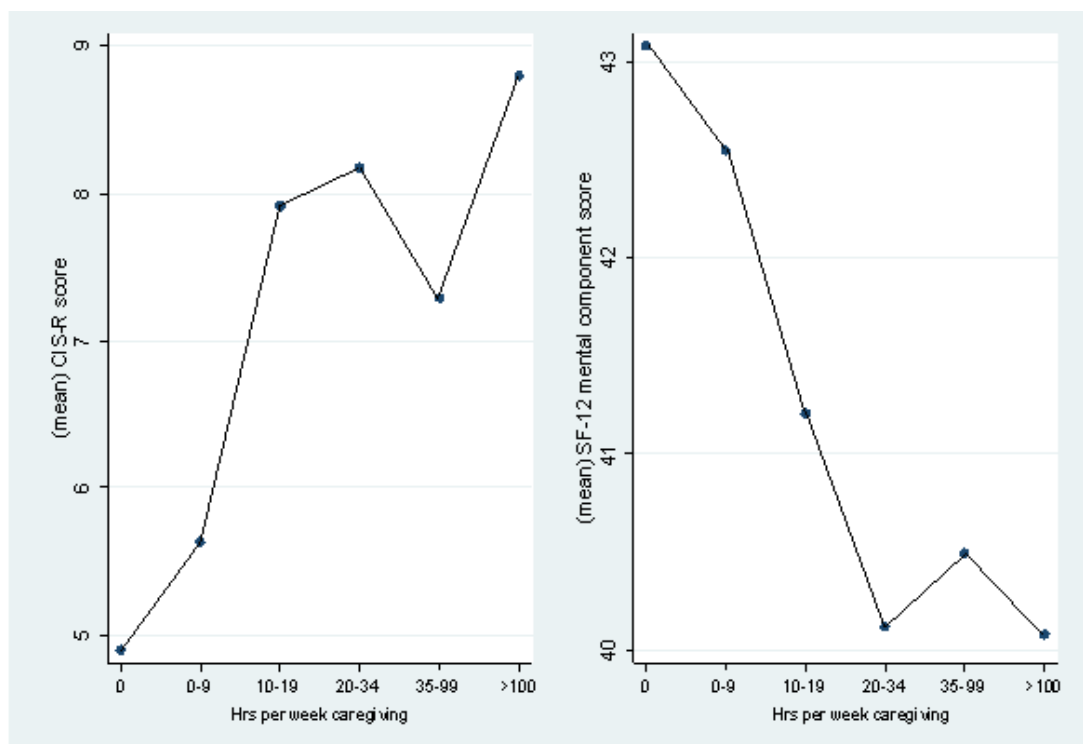
**Table 7: SF-12 mental health summary scores by amount of caregiving (adjusted analyses)**

Amount of caregiving (hrs per week)	SF-12 mental summary score, weighted mean	Unstandardised co-efficient (B)	95% CI for co-efficient	t-statistic	Significance
Non-caregivers	42.9				
0-9	42.6	-0.7	(-1.03, -0.29)	-3.55	p<.0001
10-19	41.4	-2.0	(-2.92, -1.08)	-4.26	p<.0001
20-34	40.4	-2.5	(-3.74, -1.28)	-4.03	p<.0001
35-99	40.6	-2.6	(-3.81, -1.34)	-4.09	p<.0001
≥ 100	39.7	-4.1	(-5.92, -2.26)	-4.40	p<.0001

**Figure 9: Plot of residuals from adjusted regression of perceived mental health scores (SF12, MCS)**



**Figure 10:** Psychiatric symptom score and perceived mental health by amount of caregiving



***Mental health: proportions of carers meeting clinical thresholds for disorder***

Further evidence in support of the relationship between caregiving and poorer mental health outcomes was derived when the proportions of individuals reaching clinical thresholds for psychiatric symptoms were compared (**Table 8, overleaf**). Participants engaged in more caregiving (>20hpw) were twice as likely as non-caregivers to report CIS-R scores of 12 or more. This effect on the CIS-R score was paralleled by a consistent excess of every one of the six diagnostic categories of common mental disorder (**Table 10, p. X**). Overall, when tested with Chi-squared, the higher rates of clinical threshold symptom scores and psychiatric diagnoses amongst caregivers was significant ( $p < .0001$ ).

**Table 8: Psychiatric symptom score (CIS-R) by amount of caregiving: proportion of individuals meeting clinical thresholds for disorder ( $\geq 12$ )**

Amount of caregiving (hours per week, hpw)	Weighted %, (95% CI) <b>Bold indicates significance</b>				
	CISR Overall score four-fold categorisation				
	0-6	7-11	<b>12-17</b>	<b><math>\geq 18</math></b>	Total
Non-caregivers	70.40 (68.88, 71.88)	16.35 (15.17, 17.60)	<b>6.73</b> (5.99, 7.54)	<b>6.52</b> (5.87, 7.24)	100
0-19hpw	63.49 (60.69, 66.20)	17.79 (15.76, 20.02)	<b>9.34</b> (7.74, 11.25)	<b>9.38</b> (7.94, 11.06)	100
$\geq 20$ hpw	50.18 (44.55, 55.79)	21.29 (16.71, 26.72)	<b>13.50</b> (9.97, 18.03)	<b>15.03</b> (11.85, 18.89)	100

Overall:  $\chi^2 = 94.65$ ,  $df = 6$ ,  $p < .00001$

### *Physical health*

Caregivers reported experiencing a statistically higher mean number of physical illnesses in the preceding year than non-caregivers (**Table 9**).

**Table 9: Mean number of physical illness in preceding year by amount of caregiving**

Amount of caregiving	Mean number of physical illnesses in preceding year	95% CI for coefficient	t-statistic	Significance
Non-caregivers	0.86	(0.82, 0.90)		
0-19hpw	0.98	(0.92, 1.04)	3.2	$p < .005$
$\geq 20$ hpw	1.16	(1.02, 1.30)	4.11	$p < .0001$

However, while group differences were significant when tested in unadjusted regression analyses ( $F(5,256) = 4.55$ ,  $p < .001$ ,  $R^2 = .004$ ) they ceased to be so in a model controlling for potential confounding factors. Unadjusted regression analyses of the relationship between

**Table 10: Rates of primary psychiatric diagnoses (ICD-10) by care-giving status**

Care-giving status	Weighted %, (95% CI), <b>Bold indicates significant difference</b>							
	ICD-10 primary diagnosis							
	No disorder	Mixed anxiety and depressive disorder	Generalised anxiety disorder	Depressive disorder	Phobia	Obsessive-compulsive disorder	Panic disorder	Total
Non care-givers	<b>85.56</b> (84.49, 86.56)	<b>7.96</b> (7.16, 8.85)	2.28 (1.90, 2.74)	2.21 (1.83, 2.67)	0.80 (0.60, 1.08)	0.43 (0.27, 0.68)	<b>0.76</b> (0.60, 1.08)	100
Care-givers (>0hpw)	<b>78.37</b> (76.20, 80.40)	<b>11.67</b> (10.05, 13.50)	3.35 (2.62, 4.27)	2.75 (2.10, 3.59)	1.34 (0.81, 2.21)	0.84 (0.46, 1.55)	<b>1.68</b> (1.14, 2.47)	100

Overall:  $\chi^2 = 58.46$ , df= 6, p<.00001

hours spent caregiving and standardised scores for perceived physical health (SF-12 physical component summary scores, PCS) were also carried out. In comparison to non-caregivers, people engaged in higher amounts of caregiving reported significantly poorer perceived physical health ( $B = -1.26$ , 95% CI  $[-2.42, -0.11]$ ,  $t = -2.15$ ,  $p = .03$ ). This association was non-significant for lower amounts of caregiving ( $p > .05$ ). Following the introduction of confounding factors in a multiple linear regression (mental health summary scores, sex, age, ethnicity, marital status, employment status, daily alcohol consumption, body mass index, and social support), higher levels of caregiving were actually associated with better physical health summary scores, albeit not significantly so (0-19 hpw:  $B = 0.31$ , 95% CI  $[-0.25, 0.87]$ ,  $p > .05$  and  $\geq 20$  hpw:  $B = 0.96$ , 95% CI  $[-0.19, 2.11]$ ,  $p > .05$ ). The overall model however was significant ( $F(17, 244) = 98.22$ ,  $p < .0001$ ,  $R^2 = .24$ ) and participants' age, employment status and body mass index contributed most to the 24% variance accounted for in PCS scores.

## 6.6 Discussion

### *The frequency of caregiving*

One in four people aged over 16 in households identified themselves as caregivers during the APMS 2007 interviews. This is twice the rate reported by the Survey of Carers in Households (SCH), 2009/2010 (10.9%) and by the UK Census 2001 (12.3%). This discrepancy might relate to the survey questions, to context, or to the sampling design. The SCH 2009/2010 notes for example the potential for its methodological approach to underestimate 'lighter touch' or lower intensity caregiving (*Department for Health, Survey of Carers in Households, 2010*). Frequencies obtained by interviews conducted with a respondent 'nominated by the householder' (as was the case for the SCH) are likely to differ from those where all members of the household are interviewed (*King et al., 2010*). Both the General Household Survey (2000/2001, *Maher et al., 2002*) and the British Household Panel Survey (2007, *Heitmueller et al., 2008*) used the latter approach, and obtained somewhat higher estimates for the caregiving population, at 16.1% and 17.0%



respectively. In the APMS, one member was selected at random from each household and weighting was used to render the sample representative of the adult population in England. Using this robust approach, it also reports a larger caregiving population.

The excess in the frequency of caregivers is restricted to those engaged in fewer caregiving hours per week (0-19hpw). Rates of higher amounts of caregiving (>20 hpw) are relatively consistent (APMS 2007: 4.4%, SCH 2009/2010: 5.2%; Census 2001: 3.9%, GHS 2000: 4.1%). Contrary to the Census which identifies individuals taking part in at least 1 hour per week (hpw) caregiving, the APMS includes 0hpw in its first category. This allowed for people engaged in variable amounts of care over a monthly period, and may account for the higher frequency of individuals taking part in lower amounts of caregiving. Political and media attention to informal caregiving may also have influenced public acknowledgment of everyday activities as constituting ‘caregiving’. However, this might be expected to affect all surveys equally. If, nevertheless, the difference indicates early-stage caregiving in relation to an ageing population, it should be noted. Corresponding increases in higher-intensity caregiving might in consequence be expected in the future. Although age-standardised rates of caregiving from the 2011 Census (completed after the APMS 2007) are yet to be released, provisional analyses suggest that the greatest rate of growth in the caregiving population over the last 10 years has been observed in those providing more than 20 hours per week of care. At least for higher levels of care, most caregiving relationships in the APMS 2007 involved the provision of care by older participants. This is reflected in the predictive influence of age in the multivariate regression of physical health outcomes.

### ***The impact of caregiving***

As predicted, caregiving was significantly associated with poorer mental health outcomes. The null hypothesis is rejected as this relationship remained robust in regression analyses even after the inclusion of confounding factors, yet the causal direction is unclear. Increased psychiatric symptomatology and rates of common mental disorder in caregivers

may reflect shared vulnerabilities which have led biologically and socially related care-recipients to require support themselves. However, a number of considerations may suggest that the mental health correlates are responses to the caregiving role. First, a relatively objective measure of amount of caregiving (number of hours per week) was used, as opposed to scaled measures of subjective feelings of burden (*Buyck et al., 2011*) which are likely to have a higher correlation with psychological distress (*Vitaliano et al., 2003*). Second, a significant and sizeable dose effect in relation to amount of time devoted to caregiving per week was observed, with more pronounced declines in mental health observed at upwards of 10 hpw and also at greater than 100 hpw spent caregiving. This is consistent with studies analyzing trajectories of caregiving in earlier national samples (*Legg et al., 2012; Hirst, 2005*), and is difficult to interpret in terms of self-selection of psychiatrically disadvantaged people into the caring role. Third, again in line with previous studies, the relationship reported between caregiving and physical health was inconsistent, being significantly affected by moderating factors. The caregivers in question are older than the national average, and older populations generally have worse physical but better mental health than the average (*Spiers et al., 2011; Jorm, 2000*). The fact that this pattern was so different in carers is difficult to explain in terms of selection, and therefore makes a direct effect of the caregiving role on mental health a more likely explanation.

Caution is nevertheless advisable in interpreting the clinical significance of the dose-response relationship between hours per week spent caregiving and severity of psychiatric symptoms. A limitation associated with categorising caregivers according to hours spent caregiving is that it may implicitly suggest a uniform impact of care associated with one unit hour. Caring for people with mental as well as physical health problems is known to be associated with higher levels of distress than caring for those with physical health issues alone (*Singleton et al., 2002*). This distress may accordingly be experienced at lower amounts of caregiving, which further justifies the inclusion of individuals who identify as carers but who quantify their regular level of caregiving activity at less than 1 hour per week

(0hpw). The observed dose-response relationship may therefore be moderated by variables such as care recipient illness, kinship and face to face contact time. It may also be affected by changes in available resources and competing demands. A partial reversal in declining CIS-R scores associated with increased caregiving hours was observed at the second highest amount of caregiving (35-99 hpw). This might be explained by changes in compounding stressors including employment as people retire and take on greater caregiving activities associated with older age. A substantial increase in the proportion of people not having worked in the last year was observed in those endorsing 35-99hpw caregiving by comparison to lower amounts of care (**Table 4**). It may alternatively indicate some psychological adjustment to the stresses associated with caregiving as hypothesised in stress-appraisal-coping models (*Lazarus & Folkman, 1984*).

### ***Limitations***

The data relied on self report, without collateral corroboration. This may have led to under-reporting of physical conditions: participants may have had undiagnosed symptoms, or have been unaware or forgetful of a previous diagnosis. The requirement that physical conditions had to have been diagnosed by a health professional however should have increased consistency in self reports of physical conditions by constraining the ailments included. The validity of the findings is also supported by the significant correlations observed between perceived and observer-rated measures of physical and mental health. In addition, self-reported mental health has intrinsic value as an indicator of psychological distress, particularly given the central role of subjective carer appraisals in cognitive models of carer burden or impact of care (*Szmukler et al., 1996; Lazarus & Folkman, 1984*).

The study also relied on self-report for measuring time spent caregiving. Whilst this method has been validated, it may lead to overestimations or underestimations of caregiving levels and is less accurate than diary techniques (*Van den Berg & Spauwen, 2006*). Additionally, the APMS survey did not assess some important characteristics of caregiving roles that could not therefore be analysed in relation to physical and mental health. These included

the basis of the relationship between caregiver and care recipient, whether they lived together, the duration of the caring role, and the type of illness suffered by care recipients. The findings therefore relate to the generality of caregiving: caring for people with specific problems might result in specific patterns of impact. Finally the data were obtained cross-sectionally, which limits causal inference.

### ***Implications***

The results indicate, first, the need for pre-emptive policies to identify carers at an early stage and to target support services appropriately. This raises the issue of how best to identify and communicate with carers at an early stage. Second, whilst varying definitions of caregiving might lead to variations in reported frequency, the study affirms that objective measures of caregiving demand (hpw) are informative. Their proposed inclusion is therefore supported in quick assessment instruments being developed for carers (*Cameron et al., 2011; Cormac & Tihanyi, 2006*). Finally, understanding differences in the impact of caregiving roles in relation to individuals with different physical and mental health conditions will help services to provide targeted information and support to enable families to cope effectively.

## **Chapter 7: Study 2: ethnic differences in caregiving processes in first-episode carers**

### **7.1 Study 2: Aims and hypotheses**

Study 2 focused on carers of individuals who had recently experienced a first-episode of psychosis who self-identified as white British, Scottish, English, Irish or 'other' (WB) or as black African, black Caribbean, black British or black 'other' (BA\_BAC) at the time of assessment. Ethnic group differences were investigated in perceived impact of care, appraisals of service user' behaviours and of illness, coping styles, levels of distress and Expressed Emotion. As discussed, the literature on cultural differences in caregiving processes is diverse. There are few studies specifically addressing the experiences of carers of individuals with psychosis from black African and black Caribbean communities in the UK. The analyses were therefore designed, firstly, to test the following primary hypotheses emerging principally from studies of African American individuals and other ethnic minorities.

- It was predicted that BA\_BAC carers would be more likely to report positive appraisals of caregiving (*Lawrence et al., 2008*).
- In addition, BA\_BAC carers were predicted to perceive fewer negative consequences from illness and to endorse more external illness causes (*McCabe & Priebe, 2004, Guarnaccia & Parra, 1996*).
- BA\_BAC carers were also expected to report higher levels of Warmth towards their relative, in comparisons of EE, than WB carers (*Lopez et al., 2009; Rosenfarb et al., 2006a; Janevic & Connell, 2001*).

In a secondary exploratory section of bivariate associations in cognitive processes, the hypothesis was examined that EE would be more strongly associated with perceived burden in WB carers than BA\_BAC carers (*Weisman et al, 2006; Rosenfarb et al., 2006a*). A potential role for sleep was also investigated in mediating the relationship between carer burden and distress, based on previous findings in samples of general carers (*Phillips et al., 2009*).

## **7.2 Methodology**

### ***Ethics***

Ethical approval was granted by the Berkshire Research Ethics Committee on 27<sup>th</sup> October 2010; reference number **10/H0505/79**, **Appendix 2**. To enable recruitment through clinical teams further permissions and site approvals were obtained from the following NHS Trust Research and Development Offices: East London (**ReDA ref: JB1210/1**), North London, Oxleas and South London and the Maudsley.

Clinical teams were consulted prior to any service user or carer contact. An invitation letter and information sheet was issued to all potential participants (**Appendices 3 & 4**). Care co-ordinators sought verbal consent from individuals before telephone contact from the investigator. Service-users had to approve contact with their carer. The purpose of the studies was explained in full at least 24 hours before attending to take part, and the voluntary nature of the study and right to withdraw at any time was reiterated in every communication. All participants completed and signed a consent form, supported by an information sheet, and in the presence of the investigator who was available to answer further questions (**Appendix 5**).

Carers were additionally provided details of the *mentalhealthcare.org.uk* website for further information and support for families, and carers and were contacted 1 week following participation for feedback.

All participants were assigned a research number for identification. Personal contact information was stored independently from all task results. Electronic files were secured with password encryption on a private computer. Hard copy files were kept within the Psychology Department of the Institute of Psychiatry. Participants were reimbursed up to a maximum of fifteen pounds sterling for their involvement and travel costs. However, some individuals opted to take part without reimbursement.

### Recruitment

Recruitment took place during the period April 2011 – Feb 2013 via Early Intervention in Psychosis teams in ten London Boroughs with high ethnic minority populations: Barking and Dagenham, Bromley, Croydon, Havering, Lewisham, Bexley, Redbridge, Southwark, Tower Hamlets and Waltham Forest. Care co-ordinators identified potential participants to receive information about the study based on ethnicity registered on the Electronic Patient Records system, on most recent diagnoses of the service user, on known or speculated level of carer contact and on additional relevant information including current admission status of service users. Approximately 270 service users and carers were invited to participate in the study (**Table 11**). An estimated five percent (5%) of individuals responded immediately via the reply slip. However, the majority of participants were recruited following further clarification of the study details by telephone, or directly via presentations given at carers' groups. There was a slight discrepancy in the rates of participants recruited across the two ethnic groups (BA\_BAC = 1 in 3, (40/118), WB = 1 in 2, (37/74). Overall, approximately 1 in 4 of the families who were recommended by care co-ordinators to receive details about the study took part.

**Table 11: Study 2: recruitment figures**

EI Service	No response/declined/excluded		Participants		Total Referred
	BA_BAC	WB	BA_BAC	WB	
Barking & Dagenham	0	2	0	3	5
Bromley	3	1	3	1	8
Croydon	39	22	7	7	75
Tower Hamlets	2	1	0	2	5
Havering	3	6	3	5	17
Lewisham	23	13	7	3	46
Bexley	10	13	2	8	33
Redbridge	2	2	5	3	12
Southwark	31	9	10	2	52
Waltham Forest	5	5	3	3	16
Totals	118	74	40	37	269

The target sample (white British and black African, Caribbean and black British carers) was representative of the demographics of central South London service users. North East and East London EI services had a higher proportion of Indian, Bangladeshi, Pakistani and Asian service users and carers. The South East London services in Bexley and Bromley had a higher proportion of white British clients.

### ***Inclusion/exclusion criteria***

The following criteria were applied during the screening process to select participants. In addition to those who declined, attrition in recruitment conversion rates are partially explained by this process.

- carers had to be identified by both service users and themselves as fulfilling a main caregiving role
- they had to have maintained regular contact with service users, of at least 10 hours per week, with a minimum of one face-to-face interactions per week, over a period of at least 3 months
- carers had to self-identify with the ethnicities specified in the study
- carers with a primary diagnosis of substance abuse, organic disorder or learning disability were excluded from the study
- those with insufficient English to complete questionnaire measures were also excluded from the study

The parameters selected for identifying carers were consistent with previous studies in psychosis (*e.g Psychological Prevention of Relapse in Psychosis study, PRP, Garety et al., 2008*). Additional support for using an interpersonal contact threshold of 10 hours per week was subsequently observed in Study 1: the point at which the self-reported mental health of carers significantly declined within the context of a dose response relationship between weekly hours spent caregiving and distress.

### ***Assignment of ethnicity***

Ethnicity was self-ascribed based on Census 2011 recommendations (*Office for National Statistics: Ethnic group statistics: a guide for collection and classifications, 2003*). Individuals were grouped as White: English/Welsh/Scottish/Northern Irish/British/Irish or any other white background (WB) as well as Black/African/Caribbean/Black British or any other Black/African/Caribbean background (BA\_BAC). In accordance with Census criteria



this was defined as anyone born in the Caribbean or sub-Saharan Africa or anyone whose parents, grandparents or parental family originated there. Further information on individual place of birth and parental place of birth, as well as time spent in the UK (years) was collected as part of a demographic screen to identify generational status. Participants also completed a short measure of ethnic identity and affiliation based on their ‘country of origin’ (*Multi Ethnic Group Identity Measure, Phinney 1992, see below*).

### ***Measures***

A standard form was used to collect information on carers’ socio-demographic characteristics. The data recorded included gender, age, ethnicity, employment status, level of education, weekly income, living arrangements, marital status, relationship to the service user and average weekly face-to-face contact. Additionally, carers reported service-user characteristics including age, gender, illness time in weeks (calculated from first presentation at emergency services in which a diagnosis was given or registration date with early intervention teams) and number of admissions. These illness details were verified with clinical teams. Measures were selected for the study based on reliability, validity and previous application within psychosis samples. The measures were piloted with two carer ‘consultants’ from a South London carers group. The battery is detailed below and shown in full in **Appendix 6**.

### ***Impact of care /appraisals of caregiving***

#### ***Experience of Caregiving Inventory (ECI) Szmulker et al., 1996***

The Experience of Caregiving Inventory is a 66-item questionnaire designed to measure caregiving experiences, with a particular focus on subjective appraisals made by relatives of patients with severe mental illness. It is divided into 2 sections; the first contains a series of 52 statements relating to thoughts a carer may have had about their caregiving role or patient behaviour; for example ‘*his/her dependence on you*’ or ‘*him/her always being at the back of your mind*’; the second includes a further 14 items relating to thoughts about patient symptoms e.g ‘*withdrawn*’ or ‘*unpredictable*’. Responses are rated on a 5-point Likert scale

reflecting the time spent thinking on these in the past month (0-4: never, rarely, sometimes, often, nearly always). The ECI departs from alternative instruments designed to measure carer ‘burden’ by operationalising caregiving within a stress-coping theoretical framework (Szmukler *et al.*, 1996; Schene *et al.*, 1994; Platt, 1985). Developed and validated within populations of carers of individuals with schizophrenia, it therefore emphasises the importance of carer’s internal processes in dictating distress and also captures positive aspects of caregiving.

The self-report questionnaire consists of 10 subscales: eight negative (difficult behaviours, negative symptoms, stigma, problems with services, effects on the family, the need to provide back-up, dependency, loss) and two positive (rewarding personal experiences, good elements of the relationship) which can be summed to provide overall scores for subjective burden and positive experiences from caregiving.

The negative subscale (**ECI\_neg**) used in the present study is a sum score of 52 items (range = 0-208). The positive subscale (**ECI\_pos**) is a sum score of 14 items (range = 0-56, Smukler *et al.*, 1996). The instrument has demonstrated good reliability and validity with family members of those with psychosis (Joyce *et al.*, 2000) and the constructs and content have been deemed both acceptable and important to carers (Harvey *et al.*, 2008). The scale has additionally been validated across cultures (Gonçalves-Pereira *et al.*, 2013; Jorge & Chaves, 2012; Flora *et al.*, 2008; Tarricone *et al.*, 2006).

#### ***Illness beliefs/carers appraisals of illness***

##### ***Brief Illness Perceptions Questionnaire (BIPQ) Broadbent, 2006***

The Brief Illness Perceptions Questionnaire (BIPQ) is a 9-item questionnaire which assesses cognitive and emotional representations of illness in individuals with physical or mental health issues (Sirri & Grandi, 2012; Kinderman *et al.*, 2006). It was developed as a short-form alternative to the Illness Perception Questionnaire – Revised (IPQR) (Weinman *et al.*, 1996). The first 5 questions in the BIPQ address each of 5 core cognitive representations of

illness: beliefs about the *consequences* of illness or how much it affects the patient's life (Item 1), expected *timeline* or duration of illness (Item 2), judgement about *personal control* over the illness (Item 3) and the efficacy of *treatment or medical control* (Item 4), and *identity*, the degree to which a person experiences symptoms and how they label their problems (Item 5). These five cognitive dimensions are rooted in Leventhal's Self Regulatory model (*Broadbent et al., 2006, Leventhal et al., 1991, 1984; Leventhal & Nerenz 1985*).

Each of the items is scored on a 10-point scale, with increases in score representing linear increases in the item measured. This is also the case for 3 of the 4 remaining questions which address emotional representations and understanding of illness: degree of concern (Item 6), comprehensibility (Item 7) and emotional impact (Item 8). The final item assesses causes of illness. Individuals are asked, by means of open ended responses, to list the three most important causal factors in their illness in rank order. This approach is superior to those scales which assume that the first response given is held as the principal causal belief.

Results indicate the BIPQ has good test-retest reliability (within a sample of renal outpatients, 3 and 6 week time periods, Pearson's correlations between  $r=0.48$  and  $0.75$ ,  $p<0.001$ ) and moderate to good associations with the IPQ-R (*Broadbent et al., 2006*). Predictive validity has been explored in relation to 3 month outcomes for myocardial infarction patients, with a slower return to work being significantly associated with higher concern ( $r=.43$ ;  $p=0.03$ ) and with higher treatment control beliefs ( $r=.44$ ;  $p=0.03$ ). There is some evidence of the translatability of the BIPQ and its ability to differentiate cultural differences in illness beliefs, although further development has been recommended (*Pacheco-Huergo et al., 2011; Sanders et al., 2011*). In line with modifications made to the IPQ-R for use with carers of schizophrenia patients (*Barrowclough et al., 2001; Lobban et al., 2005*) minor text adaptations were made to the BIPQ for the present study to create a carer version (e.g how much control do you believe your relative has over their illness).

The single item assessing perceived consequences of the illness for the carer (**BIPQ\_conseq**) was used in Study 2 together with the items measuring perceived patient control over their illness (**BIPQ\_control**) and the expected duration of illness (**BIPQ\_timeline**). This was based on the literature relating to attributions in carers. Responses to the causal items were analysed categorically (e.g. genes, stress) and were verified by two raters.

### ***Coping***

#### ***Brief COPE Inventory (B-COPE)***

***Carver, 1997***

The Brief COPE Inventory comprises 14 scales (2 items each) that measure a range of different coping strategies, approaches or styles in response to stressful experiences or situations. The items reflect those thoughts and actions which would be deemed positive or adaptive (e.g. *Positive Reframing*) as well as negative or potentially dysfunctional coping responses (e.g. *Substance Use*), (Carver, 1997). Each scale assesses a different conceptual component of coping, as derived from previous coping scales (e.g. the Ways of Coping Scale, Multidimensional Coping Inventory) and the literature used to develop the precursor (extended) full COPE scale (Carver *et al.*, 1989; Schwarzer & Schwarzer, 1996). The components are all additionally framed within Lazarus and Folkman's models of coping (Zeidner & Endler, 1996; Lazarus & Folkman, 1984) and assess aspects of either *problem-focussed coping*, targeted at altering external sources of stress, or *emotion-focussed coping*, which aims to manage or alleviate internal distress associated with a situation or problem.

Individuals are asked to judge how often *over the past 3 months* they feel they have employed a particular strategy. Response options range from 0 – '*I have never done this*' to 3 – '*I have done this a lot*'. Scores on each of the scales (summed 2 items) are used independently in analysis as continuous data. No 'overall' score for the scale is produced. Aggregate scores or higher order factors (for example 'Avoidant' coping; comprising the behavioural and emotional disengagement, denial and substance use scales) have however been used in psychosis samples where correlation analyses support the grouping of scales

(e.g. Onwumere et al., 2011; Kuipers et al. 2006; Raune et al., 2004; Carver et al., 1989). Data on the reliability and validity of the Brief COPE was derived from a convenience sample of community residents responding to Hurricane Andrew; however an effort was made to ensure ethnic and socioeconomic diversity (Carver, 1997). Test-retest scores (3, 6 months and 1 year post hurricane) for each of the scales exceeded alpha values of 0.5; with all exceeding 0.60 except for Venting, Denial, and Acceptance.

In line with guidance from the authors (Carver, 2007, retrieved 2010), minor text adaptations were made to the Brief COPE for use with psychosis patients and their carers. For example the *Acceptance* item 'I've been accepting the reality of the fact that it has happened' was altered to 'Accepted the problem had happened and that nothing can be done to change it'. Subscale correlations were inspected to establish 'higher order' factors. The mental distraction, behavioural disengagement, denial and substance use scales (8 items) were combined to give an overall avoidant coping score (**COPE\_avoid**, range = 0-24), the religious coping scale (2 items) was used (**COPE\_relig**, range = 0-6) and the acceptance, active coping, planning and positive reframing scales (8 items) were combined to give an overall score for positive or adaptive coping (**COPE\_posit**, range = 0-24).

### ***Quality of the caregiving relationship***

#### ***Camberwell Family Interview Schedule (CFI)***

***Vaughn & Leff, 1976a***

The CFI is a semi-structured interview that is used with relatives and formal carers of psychiatric patients to assess their attitudes and reported behaviours towards a patient. The probes in the standardised schedule are designed to encourage free-flowing speech and to gather information about particular areas relating to the emotional quality of the relationship. These include details of illness onset and development as well as contact with the patient, perceived strength of the relationship, frequency of irritability or quarrelling and patient symptomatology, in the previous 3 month period.

Subjective reports of feelings, as well as expressions of positive or negative emotions in the prosodic aspects of speech (e.g tone, pitch and speed of voice) are used to make quantitative ratings on 5 scales that produce an index of Expressed Emotion (EE). Interviews are audio taped and then coded on: *Criticism* (**EE\_CC**, a frequency count of comments); *Hostility* (a four point categorical scale, 0-3); *Emotional Over-involvement* (**EE\_EOI**, a six point, 0-5, ordinal scale); *Warmth* (**EE\_WA**, a six point, 0-5, ordinal scale) and *Positive Comments* (a frequency count). A classification of 'high EE' is made if six or more critical comments are noted, if there is evidence of any hostility (score 1–3), and/or if a score of 3 or more is obtained on the EOI scale (Vaughn & Leff, 1976a).

The interview and ratings system were developed as part of a series of studies that investigated how to rate emotional relationships reliably, and then used this methodology to be able to quantify the effect of family environments on the course of schizophrenia (Brown and Rutter 1966). These early studies established that for people with schizophrenia, returning to a high EE household after hospital discharge predicted subsequent relapse by 9 months (Brown *et al.*, 1972; Brown & Rutter, 1966). The research explored multiple domains of relationship functioning in order to derive the key scales which now have become established as Expressed Emotion (EE). More recent meta-analyses demonstrate that EE is a consistently robust predictor of patient outcomes (mean effect size;  $r = .30$ ,  $P < .0001$ ; significance reported in 89% of 27 studies from (Butzlaff & Hooley, 1998, following Bebbington & Kuipers, 1994). Criticism, which captures qualitative feelings of dislike, disapproval or resentment, and EOI, which rates intrusiveness, over-concern or over-protectiveness are the main scales in terms of predictive power for patient outcomes.

The CFI has shown predictive utility across languages and cultures (Kuipers, 1994,1992). Yet there remain questions as to the interpretation of the ratings system for different ethnic groups (López *et al.*, 2009; Bhugra & McKenzie, 2003; Cheng, 2002) For example, certain studies have failed to report an association between critical comments and relapse at any cut-off point in African American groups (Tompson *et al.*, 1995; Moline *et al.*, 1985). Due to its

predictive power and the richness of the information it provides, the CFI remains the ‘gold-standard’ instrument for deriving EE categorisation (Hooley & Parker, 2006). However, the time taken in administration (60-90 mins) as well as training and execution in coding, remain an issue for research and in particular for clinical applications. As a result, a number of shortened and self-report alternatives have been, or are being, developed (Medina-Pradas et al., 2012; Van Humbeeck et al., 2002).

#### ***Carer health and wellbeing/distress***

##### ***RAND 36-item Health Survey 1.0 (SF36)***

***Ware & Sherbourne, 1992***

The SF-36, published by the RAND Corporation, is a self-report questionnaire assessing general health and wellbeing. It is one of the most widely evaluated generic health measures, translated into over 100 languages and is reported to account for 10% of all patient health outcome studies before 2000 (Garratt, 2002). It was developed as part of the Medical Outcomes Study (MOS), a 2-year (1986-1987) multi-centre (Boston, Chicago, Los Angeles) multi-stage project investigating quality of life indicators for individuals engaged at various points within the State and private health care systems (Stewart & Ware, 1992; Ware & Sherbourne, 1992). A central aim of the MOS was to address the requirement for a standardised measure of health outcomes for diverse patient and general population groups. The original MOS schedule included 116 core items selected to represent the physical and mental health dimensions of an empirically supported conceptual model of functioning and wellbeing.

The shortened version of this schedule, used in the present study, was devised by Ware and Sherbourne in 1992 and includes a selection of 36 original items, which demonstrated reliability, validity and sensitivity in discriminating changes across patient groups (McHorney et al., 1994; McHorne et al., 1993). The items form 8 health domains that are in turn used to calculate aggregate scores for physical and mental health, which were used in Study 2 (Wilson et al., 2000; Ware et al., 1998; Hays et al., 1993). The *Physical Component Summary Score (SF36\_PCS)* was comprised of the subscales for physical functioning, role

limitations due to physical problems, bodily pain and perceived general physical health. The *Mental Component Summary Score (SF36\_MCS)* including scores for the questions on vitality, role limitations due to personal or emotional problems, social functioning and general mental health. A single item assessing perceived change in health over the last year is also part of the schedule.

Debate continues regarding the best means by which to score the SF-36 (*Hawthorne et al., 2007; Ware et al., 1995*) for example how to weight items and whether or not to use standardised (0-100 scale) or norm-based scoring (linear T-score transformation with mean = 50 and s.d = 10). An updated, licensed version of the survey (SF36v2, Quality Metric) is also now available. However, the RAND SF-36 was selected due to reported use and reliability both within carer groups (*Gutiérrez-Maldonado et al., 2005*) and patients with schizophrenia (*Leese et al., 2008*). In addition, the main amendments made in version 2 (i.e layout changes and comparability with translations and cultural adaptations) were unnecessary for this project. Norm-based scoring was employed using US population norms (the specific algorithms used to calculate scores are provided in **Appendix 7**). Evidence suggests the applicability of US algorithms to UK populations and normative data from the UK is over 20 years old (*Burholt & Nash, 2011; Jenkinson, 1999*). The SF-36 does however notably lack a sleep domain, despite the fact that poor or disrupted sleep patterns are consistently associated with ill health (*Hill et al., 1993; Sheldon, 1993*) and distress in carers (*Phillips et al., 2009*).

***Pittsburgh Sleep Quality Index (PSQI)***

***Buysse et al., 1989***

The Pittsburgh Sleep Quality Index is a 24-item questionnaire which enables distinction between individuals obtaining ‘poor’ versus ‘good’ quality sleep over the last month and can give an indication of patterns of sleep and areas of dysfunction. 18 of the items are self-report and were selected for the study as they are solely relevant for scoring. The items are grouped to form 7 subscales relevant to sleep quality including *Sleep Duration* (item 4) and *Sleep Latency* (items 2 & 5a) split into 4 categories (*Buysse et al., 1989*), *Habitual Sleep*



*Efficiency* (% Efficiency = number of hours slept, item 4/Number of hours spent in bed item3-item1 X 100, split into 4 categories = <65%; 65-74%; 75%-84%; >85%), *Sleep Disturbances* (frequency rated on a 4-point Likert scale: Not during the past month, Less than once a week, Once or twice a week, Three or more times per week, sum items 5b-j split into 4 categories 0, 1-9, 10-18, 19-27), *Use of Sleep Medication* (item 7 rated on a 4-point Likert scale: Not during the past month, Less than once a week, Once or twice a week, Three or more times per week), *Daytime Dysfunction* (sum score items 8 and 9, split into 4 categories, 0, 1-2, 3-4, 5-6) and overall *Subjective Sleep Quality*. Each of the items is equally weighted and scored on a 0-3 point Likert scale (with 3 being negative) (Buysse et al., 1989).

A global score (**PSQI**) is generated by summing the 7 subcomponents and was used to assess general sleep difficulties. Scores range from 0-21 with higher scores indicating poorer sleep quality and a global sum of 5 or more operating as the classification cut off for a 'poor' sleeper. The PSQI has demonstrated good internal consistency for its seven components (Cronbach's alpha = 0.83) and reliability (test-retest (timeframe unspecified) = 0.85,  $p < 0.001$ ) in a group of good and poor sleepers (Buysse et al., 1989). It addresses each of four physical domains identified within the literature as relevant to conceptual models of sleep dysfunction (sleep initiation, sleep maintenance, sleep adequacy, and somnolence) (Devine et al., 2005) and a number of studies support its sound reliability and validity (Högl et al., 2010; Harvey et al., 2008; Backhaus et al., 2002), including across ethnic groups and countries (Beaudreau et al., 2012; Aloba et al., 2007).

**Beck Anxiety Inventory (BAI)**

**Beck et al., 1988**

The Beck Anxiety Inventory (**BAI**) is one of the most commonly accepted standard measures of prolonged state anxiety, assessed by self-rating the extent to which symptoms have been experienced in the previous week, including the day of completion. 21 items incorporating cognitive and physiological components of anxiety for example 'fear of losing control' or 'heart pounding or racing' are scored on a 0-3 scale: 0= *Not at All*; 1= *Mildly* (It did not bother me much), 2 = *Moderately* (It was very unpleasant, but I could stand it), and 3

= *Severely* (I could barely stand it). Total scores range from 0 – 63 with those in the range 0 - 7 interpreted as a ‘Minimal’ level of anxiety, 8 - 15 as ‘Mild’, 16 - 25 as ‘Moderate’ and 26 - 63 as ‘Severe’. Total score analysed as a continuous variable was used in comparisons of distress levels across ethnic groups (**BAI**). The proportion of carers meeting clinical thresholds for ‘moderate’ to ‘severe’ anxiety was also examined.

The BAI was specifically developed in an attempt to capture unique symptoms of anxiety that reduce correlation with measures of depression ( $r = .48$  with measures of anxiety and  $r = .25$  with measures of depression in the original sample, *Beck et al., 1988*). As such 14 out of the 21 items included in the BAI represent somatic symptoms with the remaining 7 addressing subjective cognitions associated with anxiety and panic. Initial factor analyses proposed a two-factor structure based on the cognitive and physiological axes, subsequent factor analyses have proposed a 3-factor structure, separating those items associated particularly with ‘panic’ (*Leyfer et al., 2006; Beck et al., 1988*). The potentially preferential suitability of measures of Anxiety which place an emphasis on somatic symptoms of Anxiety has been suggested for certain ethnic minority groups (*Hunter & Schmidt, 2010*) and the factor analytic structure of the BAI has been assessed across ethnic groups (*Chapman et al., 2009*). The BAI is psychometrically robust with internal consistency (Cronbach’s alpha) reported between 0.92 and 0.94 and test-retest reliability as 0.75 (*Beck et al., 1988*). It has shown concurrent validity with other leading measures of anxiety (e.g the Hamilton Anxiety Rating Scale Revised,  $\alpha = 0.51 - 0.58$ ) and has been used extensively in clinical and non-clinical populations (*Osman et al., 1993; Steer et al., 1993*).

***Centre for Epidemiological Depression Scale (CES-D)***

***Radloff, 1977***

The **CES-D** is a self-report questionnaire assessing depressive symptoms. It was developed in the 1970s to be used primarily within the general population to measure affective state. Items were selected from longer and established scales (e.g the Beck Depression Inventory, BDI and Zung Self-Rating Depression Scale, Zung SDS) to generate a final composition of 20 questions (*Radloff, 1977*). Respondents are asked to endorse whether or not they have

felt, for example, that they were '*bothered by things that don't usually bother*' them or '*could not get going*' over the last week. The response scale is scored 0 – 3 with '*rarely or none of the time*' being equated with less than 1 day, '*some or a little of the time*' with 1-2 days, '*occasionally or a moderate amount of the time*' with 3-4 days and '*most or all of the time*' with 5-7 days. Four of the items reflect positive feelings (e.g. '*I enjoyed life*', items 4, 8, 12 and 16) and were included to test for response bias. These are reversed in scoring. Total CES-D scores therefore range from 0-60 with higher scores indicating more severe depressive symptoms. In the original studies a score of 16 or above differentiated those individuals who would meet clinical thresholds for depressive illness from non-clinical groups. Both total scores (**CES\_D**) and clinical cut-offs were used in Study 2.

Although the items in the CES-D were intended to, and do reflect, components of depressive illnesses (for example feelings of worthlessness, hopelessness, poor concentration) as defined in the Diagnostic Statistical Manual III, it has been suggested that its sensitivity and specificity in discriminating amongst clinical subtypes of depression, and between these and other Axis 1 Disorders, is less than optimal. As such the CES-D may be most appropriately considered as a general measure of distress, suitable particularly for epidemiological studies (Fechner-Bates *et al.*, 1994). The reliability and validity of the CES-D has been tested across ethnic groups and it has been translated into several languages (Naughton & Wiklund, 1993). High internal consistency has been reported in community samples ( $\alpha = 0.85$ ) and psychiatric samples ( $\alpha = 0.90$ ) (Lako *et al.*, 2011; Shafer, 2006; Weissman *et al.*, 1977; Orme *et al.*, 1986). Within a comparative study of African Americans, Anglo Americans and Mexican Americans, no significant differences were reported amongst the community samples on measures of consistency (Cronbach's alpha, Spearman-Brown split halves) or factor analytic structure (Roberts, 1980).

***Multi-Group Ethnic Identity Measure (MEIM)***

***Phinney, 1992***

The MEIM is a short questionnaire designed to assess feelings or reactions to ethnicity (as self-ascribed from a predefined list). It has been validated across ethnic groups and age groups with reliabilities typically noted above  $\alpha = .80$ . A factor analysis on a large sample of adolescents (*Roberts et al., 1999*) suggests a two factor structure to the 12-item questionnaire. The first assessing a cognitive or developmental component of ethnic identity associated with ethnic identity search and learning (items 1, 2, 4, 8, 10). The second measuring affirmation, belonging or commitment to one's ethnic identity (items 3, 5, 6, 7, 9, 11, and 12). Responses are rated on a 4 point scale (Strongly agree (1), agree (2), disagree (3), strongly disagree (4)). Overall mean scores are used for comparison. Evidence suggests that mean scores for white British populations are typically lower than for ethnic minority groups (*Phinney, 1992*).

***Computerisation of measures***

All measures were translated onto an online platform hosted at surveymonkey.com except for the Beck Anxiety Inventory which was administered in paper version in compliance with licensing restrictions. Participants chose their mode of questionnaire completion, either paper-based or computer-assisted. Online results were collected via a secure sockets layer encrypted connection. No personal details were assessed online. Datasets were identified according to participant number. The first section of the questionnaires assessing demographics was completed together with participants to demonstrate the online platform. The interviewer remained available to clarify any questions arising throughout the sessions. Online measures were piloted with three people prior to the study commencing. There is a growing body of evidence to support the suitability and validity of using computerised assessments of psychological distress and psychosocial constructs by comparison to paper-based and interviewer-administered versions (*Naus et al., 2009; Butcher et al., 2000; Lewis, 1994*). Strengths of the approach include perceived confidentiality and reduced desirability effects, increased data accuracy and missing data reduction.

### **7.3 Statistical Design**

A sample size of N=40 in each group was decided upon to test the main hypothesis of group differences in perceived impact of care based on calculations indicating that a total sample size of N=80 will have an 80% power to detect a medium effect size,  $d = 0.64$  in accordance with Cohen (1988), using a two-group t-test with a 0.05 2-sided significance level. This effect size is slightly greater than the effect size reported for differences in perceived burden between African American and White Caucasian samples in a previous US study (*Rosenfarb et al., 2006a*) The present study was based on a more widely used measure of EE within UK populations. Furthermore, a sample size of N=40 in each group has 80% power to detect correlations with  $r = 0.42$  with a 0.05, 2- sided significance level, which are marginally larger effect sizes than those reported by Raune et al. (2004) and Scazufca et al. (1996), converted from Cohen's  $d$  (*Rosnow et al., 2000*) when examining associations between subjective burden and EE.

The Shapiro Wilks test was used to verify the normality of variable distributions. Group differences were assessed using chi-squared tests for categorical variables and t-tests and Mann Whitney U tests for continuous variables. Categorical outcomes were collapsed for those variables with cell counts less than five. Bivariate correlation matrices using Spearman's rho were inspected for associations in caregiving processes across ethnic groups. Mediation analyses were conducted as specified in Baron and Kenny (1986) using linear regression. Significance of mediation was assessed using the Sobel test. Analyses were conducted in SPSS 18 (SPSS Inc. Released 2009. PASW Statistics for Windows, Version 18.0. Chicago: SPSS Inc.) and STATA 10 (StataCorp. 2007. Stata Statistical Software: Release 10. College Station, TX: StataCorp LP)

### **7.4 Carers: demographic data**

A total of 78 carers self-identifying as white British (WB) or black African, black Caribbean or black British (BA\_BAC) participated in the study. Sample demographic details based on ethnic-group split are given in **Table 12, p. 158**. Consistent with previous studies of

individuals engaged with first episode services, carers were most frequently mothers, looking after a son or daughter in the home. A high proportion of carers were living with the relative to whom they provided help and support (78%).

There were no statistically significant differences between the groups in patient or carer demographic characteristics when tested using Pearson's chi-squared, Mann Whitney U and t-tests of statistical significance ( $p > .05$ ). BA\_BAC carers were however proportionately more likely than WB carers to be single mothers looking after adult children. There was also a trend for BA\_BAC carers to be more likely to be sustaining full-time, paid employment alongside caregiving activities. Consistent with this observation, BA\_BAC carers had marginally higher levels of formal education and higher personal weekly income than WB carers in this sample. However, a higher proportion of WB carers lived in homes they owned outright, as opposed to rented accommodation, and they were less likely to live with extended family members than BA\_BAC carers in this sample. Whether or not participants lived alone, with a partner or with extended family was the only outcome variable that differed statistically significantly between the two groups when tested using Fisher's exact test ( $p < .001$ , FET).

Forty-two percent (17/41) of the BA\_BAC sample were first-generation immigrants, with a mean of 24 years spent living in the UK. Forty-nine percent (20/41) were second-generation immigrants and a further nine percent (4/41) were third-generation. Carer participants who identified as second and third-generation were either born in the UK or moved to the UK permanently under the age of 10 years old with parents. Of the WB carers, eleven percent (4/37) self-identified as white European/other and had lived in the UK for a mean of 28 years. The remainder self-identified as white British or white Irish (33/37) and were born in the UK. The ethnicities reported by the BA\_BAC carer sample were as follows: Black British = 42%, Black Caribbean/African-Caribbean = 32%, Black African = 27%. BA\_BAC carer participants scored significantly higher than WB carers on the MEIM measure of ethnic identity and affiliation ( $t = 3.78$ ,  $d.f = 74$ ,  $p < .001$ ).

**Table 12: First-episode carer characteristics: between-groups**

Proportions in %	Black/African/Caribbean/British (BA_BAC)	White British/Irish/other (WB)
MEIM score <b>t=3.78, p&lt;.0001</b>	33.7 ± 7.3	27.4 ± 6.2
No. of participants	41	37
Sex	88% female	84% female
Age (mean years)	51.2 ± 8.1	52.7 ± 9.6
Employment status:		
FT paid	37	14
PT paid	12	33
Self-employed	15	13
Unemployed/sick leave/incapacity	24	27
Retired/volunteering/studying	12	13
Formal education <sup>1</sup> :		
A level & above	52	35
GCSE/NVQ/BTEC	40	51
No qualifications	8	14
Weekly income <sup>2</sup> :		
≤ £149	27	27
£150 - £329	32	41
£330 - £459	15	8
£460 or more	27	24
Accommodation:		
Owned outright	15	35
Owned w/mortgage	42	35
Rented/social-housing	43	30
Living arrangements:		
Alone	3	8
w/ partner	27	62
w/ extended family	70	30
Marital status:		
Single	46	22
Married/civil or long term partner	52	68
Divorced/separated/widowed	2	10
Relationship to SU		
Parent	96	84
Living with SU?	78	78
Face-to-face contact (hours)	mean = 15.7 ± 10.6	mean = 19.3 ± 15.2
<b>Service user: age</b>	mean = 24.7 ± 4.5	mean = 24.7 ± 5.1
Sex	66% Male	70% Male
Illness length (weeks)	median = 88, min = 16, max = 313	median = 75, min = 7, max = 565
No. of inpatient admissions	mean = .95, min =0, max=4	mean = 1.2, min =0, max=4

<sup>1</sup> or international equivalent; <sup>2</sup> household income given in the absence of personal income

## 7.5 Results

### *Quality of CFI Ratings*

The principal investigator completed a 10-day CFI training course with Christine Vaughn (Vaughn & Leff, 1976a) and achieved the following reliability ratings across 11 audiotaped interviews: Overall EE:  $\phi = 1.00$ ; EOI:  $r_s = 1.00$ ; Critical Comments:  $r = 0.72$ ; Hostility:  $\phi = 0.81$ ; Warmth:  $r_s = .90$ ; Average across EE scales = 0.88. Inter-rater reliability for the present study was calculated between the PI and an established CFI-trained clinician on a 5% sub-sample of randomly selected recorded interviewers. Self-ascribed ethnicities for the raters reflected those included in the study respectively. Ratings were made blind to the results of all other measures. High intraclass correlations were obtained for the main EE indices analysed as continuous variables: EOI:  $r_s = .88$ ; Critical Comments:  $r = 0.96$ ; Warmth:  $r_s = .89$  and for Hostility and overall EE class examined as dichotomous variables:  $\phi = 1.00$ .

### *Ethnic group differences in impact of care, appraisals and coping*

Ethnic group comparisons were made in key cognitive processes of caregiving relevant to levels of carer distress and responses to patients, including positive and negative appraisals of caregiving (ECI\_pos, ECI\_neg), beliefs about the consequences and duration of illness, patient's control over symptoms (BIPQ\_conseq, BIPQ\_timeline, BIPQ\_control), and coping styles (COPE\_avoid, COPE\_relig, COPE\_positive). Additionally, group comparisons were made across indicators of carer distress (depression (CES\_D), anxiety (BAI), perceived physical and mental health (SF-36\_PCS, SF36\_MCS) and sleep quality, PSQI). Descriptive data on carer outcomes and results of tests of statistical significance are presented in **Table 13, overleaf**.



**Table 13: Ethnic differences in impact of care, appraisals, coping and distress**

	Total (N=78)		BA_BAC (N=41)	WB (N=37)	Sig
	Mean	Range	Mean (s.d)		
ECI_neg <sup>1</sup>	76.9	8-167	77.8 ± 30.5	76.0 ± 39.4	p=.15
ECI_pos	30.0	9-55	31.4 ± 9.9	28.6 ± 8.4	
BIPQ_conseq	6.8	0-10	7.0 ± 2.4	6.6 ± 2.8	
BIPQ_control	5.4	1-10	5.6 ± 2.5	5.3 ± 2.6	Z = -2.83, p=.005
BIPQ_timeline	6.4	1-10	5.6 ± 2.3	7.3 ± 2.5	
COPE_avoid	6.9	0-18	6.1 ± 3.8	7.9 ± 4.3	
COPE_religious	3.1	0-6	4.2 ± 2.3	1.8 ± 2.1	p=.08
COPE_positive	15.5	5-24	15.9 ± 4.6	15.1 ± 3.9	Z = -4.39, p<.001
CES_D	14.4	0-50	13.9 ± 11.4	14.9 ± 14.3	
BAI	9.4	0-48	8.8 ± 10.4	10.2 ± 10.1	
SF36_PCS	43.3	28.0-58.1	43.3 ± 5.9	43.3 ± 6.2	
SF36_MCS	37.8	9.0-52.8	36.0 ± 7.8	36.8 ± 11.0	
PSQI	6.7	1-21	6.0 ± 3.4	7.6 ± 4.9	

<sup>†</sup> see page 9 for abbreviations

### ***Impact of care and distress***

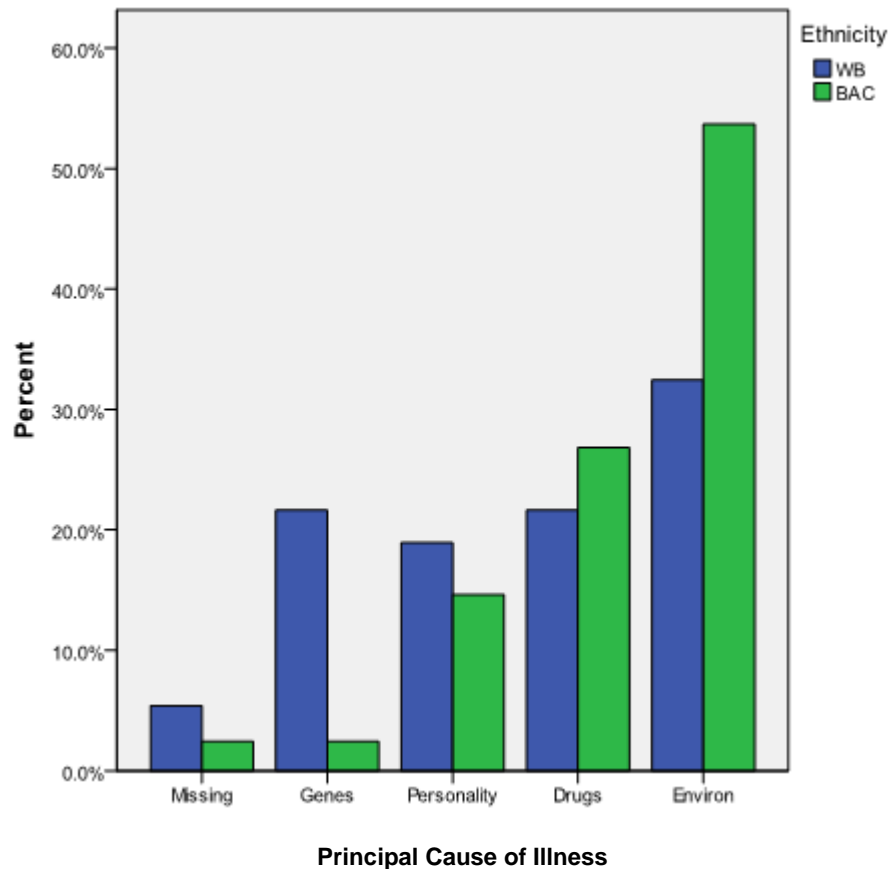
No significant group differences were observed in appraisals of caregiving, self-reported symptoms of anxiety and depression, or mean scores on the SF\_36 mental and physical health components. However, 35% of the total sample (n=78) met guideline clinical thresholds for depression (CES-D mean  $\geq 16$ ) and a further 8% met clinical thresholds for moderate to severe anxiety (BAI mean  $\geq 16$ ). Of the total sample 16% rated above clinical thresholds for both depression and anxiety.

### ***Illness beliefs***

BA\_BAC carers reported a shorter expected duration of illness (BIPQ\_timeline) than WB carers (**Table 13**). Additionally, an analysis of the principal causes given by carers for their relative's illness (**Figure 11, overleaf**) indicated greater endorsement of external or environmental illness causes as opposed to genetics, personality or emotional characteristics

of the individual. Overall, the proportion of internal versus external reasons for illness cited by carers from different ethnic groups was significant ( $Z = -2.56$ ,  $p=.01$ ). Environmental factors noted by carers included traumatic life events: physical and sexual abuse, immigration issues, relationship problems, unemployment and family stresses.

**Figure 11: Principal cause of illness cited by first-episode carers, (N=78)**



Overall:  $Z = -2.56$ ,  $p=.01$

### *Coping styles*

BA\_BAC carers were less likely to report an avoidant coping style, and significantly more likely to engage in religious coping strategies. This was despite a relatively high proportion of WB carers still reporting a religious affiliation (WB = 65% versus 83% of BA\_BAC carers). An analysis of the inter-scale correlations for the Brief COPE inventory substantiated the Positive-coping and Avoidant-coping aggregate factors used in this study (Table 14, overleaf). In addition, the correlations suggest cognitive mechanisms that may be

involved in religious coping styles including problem-focused planning and attention to the positive aspects of the caregiving experience.

**Table 14: B- COPE subscale correlations in first-episode carers, (N=78)**

Rho	C_ACT	C_PLA	C_POS	C_SUB	C_DEN	C_MDIS	C_BDIS	C_REL	C_ACP
<b>C_ACT<sup>1</sup></b>	-	<b>.619**</b>	<b>.431**</b>	.038	.044	.053	-.017	.169	.161
<b>C_PLA</b>	<b>.619**</b>	-	<b>.511**</b>	-.006	-.079	.176	.009	<b>.243*</b>	.105
<b>C_POS</b>	<b>.431**</b>	<b>.511**</b>	-	.039	.091	.189	-.008	<b>.308**</b>	<b>.317**</b>
<b>C_SUB</b>	.038	-.006	.039	-	.087	.122	<b>.360**</b>	-.137	.023
<b>C_DEN</b>	.044	-.079	.091	.087	-	.058	<b>.263*</b>	.148	.185
<b>C_MDIS</b>	.053	.176	.189	.122	.058	-	<b>.245*</b>	.191	.136
<b>C_BDIS</b>	-.017	.009	-.008	<b>.360**</b>	<b>.263*</b>	<b>.245*</b>	-	-.020	.136
<b>C_REL</b>	.169	<b>.243*</b>	<b>.308**</b>	-.137	.148	.191	-.020	-	.133
<b>C_ACP</b>	.161	.105	<b>.317**</b>	.023	.185	.136	.136	.133	-

\* significant at p<.05

\*\* significant at p<.01

<sup>1</sup>see p.9 for abbreviations

### ***Ethnic differences in Expressed Emotion***

Rates of high EE in both groups respectively were: BA\_BAC carers: 17%; WB carers = 35%. The difference in rates of high EE was reported at  $\chi^2 = 3.33$ , df = 1, p = .07. BA\_BAC carers expressed significantly higher warmth than WB carers when talking about their relative (Z = - 2.284, p < .05). All other indices of EE were rated equally when tested for median differences with non-parametric methods. However, **Table 13, overleaf** shows the proportion of carers (within-groups) rated above threshold, for overall EE and its indices: critical comments (CC), emotional overinvolvement (EOI), hostility (H) and warmth (WA). Fisher's Exact Tests were used to compare proportions across the ethnic groups. The difference in levels of emotional overinvolvement was statistically significant (p < .05, FET), with fewer BA\_BAC carers reporting attitudes and behaviours that were rated above threshold.

**Table 15: Ethnic differences in EE, proportions of carers above threshold ratings**

% (count)	High EE	CC $\geq 6$	EOI $\geq 3$	CC&EOI	H $\geq 0$	WA $\geq 3$
BA_BAC, N = 41	17 (7)	12 (5)	7 (3)	2 (1)	15 (6)	76 (31)
WB, N = 37	35 (13)	22 (8)	27(10)	14 (5)	14 (5)	54 (20)

***Service-user and carer characteristics and Expressed Emotion***

Within-group chi-squared analyses revealed few significant relationships between socio-demographics, illness characteristics and EE ratings (gender, age: of service user and carer, relationship to service user, marital status, living arrangements, number of previous admissions). BA\_BAC carers in this sample were however more likely to express high Warmth in discussing relationships with sons as opposed to daughters ( $p < .005$ , FET). Of the whole sample ( $N=78$ ), twenty-six percent (20/78) were rated as high EE using the CFI, with 30% (6/20) of these ratings made on the basis of critical comments ( $\geq 6$ ) and emotional overinvolvement ( $\geq 3$ ), a further 35% (7/20) as a result of high EOI alone and 35% (7/20) on the basis of criticism alone. Eighty-five percent (11/13) of those scoring above threshold on the criticism scale were also rated as hostile. Sixty-six percent were rated as high in warmth ( $\geq 3$ ). Mean critical comments within the total sample ( $N=78$ ) was 3.4 (s.d = 3.8; min=0, max=19). When examining relationships with sociodemographic and illness characteristics in the total sample, carers were more likely to be rated as high EE ( $p < .005$ , FET) and to report higher levels of EOI ( $\chi^2 = 2.67$ ,  $df = 1$ ,  $p = .1$ ) if they were caring for a younger adult ( $< 25$  vs  $\geq 25$  years of age).

***Ethnic differences in correlates of perceived burden***

The association between negative appraisals of caregiving (ECI\_neg), distress (SF36\_MCS and CES\_D) and critical comments (EE\_CC) was stronger for WB carers than BA\_BAC carers (**Table 16, overleaf**). Additionally, only for BA\_BAC carers, higher perceived burden was associated with lower warmth (EE\_WA).

**Table 16: Ethnic differences in correlates of perceived burden (ECI\_neg)**

rho	BA_BAC, N=41	WB, N=37
SF36_MCS	.216	-.560***
CES_D	.388*	.688***
EE_CC	.390*	.679***
EE_WA	-.452**	-.06
High_EE	.299	.414**
* significant at p<.05      ** significant at p<.01      *** significant at p<.0001		

***Ethnic differences in correlates of coping***

By contrast, Avoidant coping correlated more strongly with distress and was related to lower warmth in the BA\_BAC group, but higher criticism in the WB group (**Table 17**).

**Table 17: Ethnic differences in correlates of avoidant coping**

rho	BA_BAC, N=41	WB, N=37
SF36_MCS	-.431**	-
CES_D	.570**	.375*
BAI	.570**	.388*
PSQI	.467**	.369*
EE_CC	.116	.400**
EE_WA	-.352*	-.272
* significant at p<.05      ** significant at p<.01		

***Ethnic differences in correlates of illness beliefs***

The relationship between illness beliefs and distress also differed across the ethnic groups. Beliefs about the consequences (BIPQ\_conseq) and expected duration of illness (BIPQ\_timeline) were consistently associated with depression and distress in WB carers (**Table 18, overleaf**). Whereas in the only significant associations noted for BA\_BAC carers, perceived consequences of illness was more strongly correlated with anxiety for

BA\_BAC carers than depression (**Table 19**). Expected timeline of illness was not correlated with distress in BA\_BAC carers, for whom the duration of illness was anticipated to be shorter (**Table 13, p.160**).

**Table 18 Correlations between illness beliefs and distress in WB carers, (N=37)**

rho	BAI	CES_D	SF36_MCS	PSQI
BIPQ_conseq	<b>.421**</b>	<b>.597***</b>	<b>-.474**</b>	<b>.433*</b>
BIPQ_timeline	<b>.510**</b>	<b>.534**</b>	<b>-.356*</b>	<b>.621**</b>
BIPQ_control	<b>-.393.*</b>	<b>-.486**</b>	.236	<b>-.374*</b>

**Table 19: Correlations between illness beliefs and distress in BA\_BAC carers, (N=41)**

rho	BAI	CES_D	SF36_MCS	PSQI
BIPQ_conseq	<b>.542***</b>	<b>.328*</b>	-.122	.251
BIPQ_timeline	.152	.173	-.125	.102
BIPQ_control	-.204	-.028	-.159	.084

\* significant at p<.05 \*\* significant at p<.01 \*\*\* significant at p<.001

Notably, and in contrast to previous studies, in this sample of first-episode carers, those who believed that service users had more control over illness reported less anxiety and depression and fewer critical and hostile responses towards patients made in the CFI (**Table 20**).

**Table 20: Correlations between illness beliefs and EE in first-episode carers**

rho	High EE	CC	EOI	H	WA
<b>WB (N=37)</b>					
BIPQ_conseq	<b>.372*</b>	<b>.513**</b>	.216	.318	-.113
BIPQ_timeline	.269	<b>.376*</b>	.163	<b>.426**</b>	.001
BIPQ_control	-.306	<b>-.523**</b>	.172	<b>-.326*</b>	.116
<b>BA_BAC (N=41)</b>					
BIPQ_conseq	.097	.192	.287	.106	-.208
BIPQ_timeline	.003	.032	.194	-.019	-.092
BIPQ_control	-.127	<b>-.347*</b>	-.010	-.140	.200

\* significant at p<.05 \*\* significant at p<.01

***Cognitive correlates of Expressed Emotion in the total sample, (N=78)***

In the total sample of carers, carer burden (negative appraisals of caregiving, ECI-neg) was the strongest positive correlate of critical comments. Higher carer burden and avoidant coping were associated with less warmth (**Table 21**). However, the only significant positive correlate of warmth was religious coping. Modest positive correlations were observed between religious and positive coping ( $p=.07$ ) and warmth.

**Table 21: Cognitive correlates of Expressed Emotion in first-episode carers, (N=78)**

rho	CC	EOI	WA
ECI_neg	<b>.510**</b>	-	<b>-.231*</b>
BIPQ_conseq	<b>.341**</b>	<b>.250*</b>	-
BIPQ_timeline	<b>-.420**</b>	-	-
COPE_avoid	<b>.251*</b>	-	<b>-.346**</b>
COPE_relig	-	-	<b>.243*</b>
COPE_posit	-	-	<b>.206, <math>p=.07</math></b>

\*significant at  $p<.05$  \*\* significant at  $p<.01$

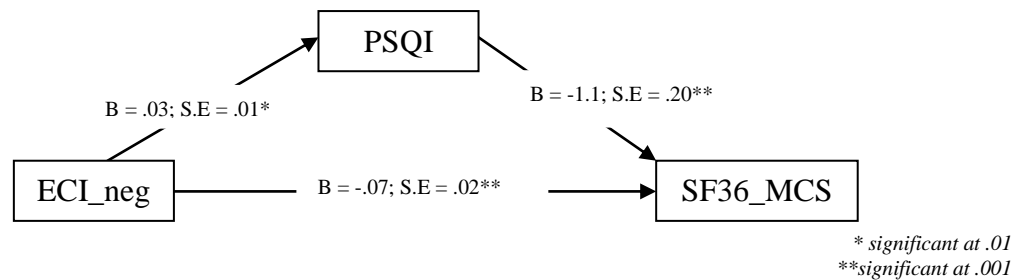
***Carer burden and distress in the total sample: a mediating role for sleep***

Of carers interviewed, 65% qualified as poor sleepers (51/78) as measured by the Pittsburgh Sleep Quality Index (mean = 6.7; s.d = 4.2, min = 1, max = 21). Analysis of a further qualitative question within the PSQI, which requires responders to specify any ‘other’ reasons for sleep disturbance (and their weekly frequency) not included within the ratings scale, revealed nearly one fifth of responders (18%) reporting a lack of sleep due to ‘worries’.

Poor sleep was associated with both negative appraisals of caregiving (ECI\_neg:  $r_s = .292$ ,  $p=.01$ ) and levels of distress (SF36\_MCS:  $r_s = -.584$ ,  $p<.0001$ ) when tested with Spearman’s correlations. In a linear regression model carer burden and poor sleep together predicted 45% of the variance in reported carer distress as measured with the SF36 mental health component summary score (adjusted  $R^2=.45$ ). The relationship between carer burden and

distress was partially mediated by sleep as illustrated in **Figure 12**. The unstandardised regression coefficient for the relationship decreased from  $B = -.115$ ,  $t = -4.87$ ,  $p < .0001$ , adjusted  $R^2 = .23$ , to  $B = -.07$ ,  $t = -3.46$ ,  $p < .001$  when controlling for sleep disturbances. The significance of this partial mediation was confirmed with the Sobel test  $Z = -5.4$ ,  $p < .0001$ .

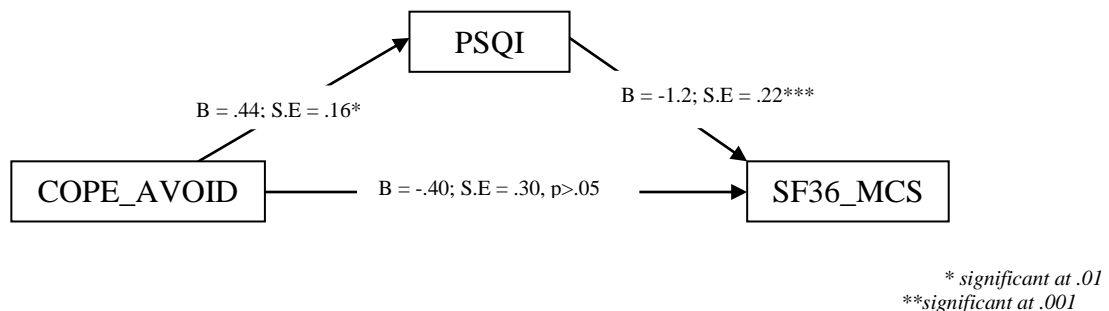
**Figure 12: Relationship between carer burden and distress as mediated by sleep: unstandardised regression coefficients and standard errors**



#### *Avoidant coping and distress*

A similar mediation model was used to examine the role of sleep in the relationship between Avoidant coping and distress in carers. Within bivariate linear regressions Avoidant coping predicted greater distress, or reduced SF36 mental health summary scores, ( $B = -.908$ ,  $t = -2.86$ ,  $p < .01$ , adjusted  $R^2 = .09$ ) and greater sleep disturbances ( $B = .435$ ,  $t = 2.80$ ,  $p < .01$ , adjusted  $R^2 = .09$ ). Poorer sleep was also associated with greater distress ( $B = -1.32$ ,  $t = -6.38$ ,  $p < .0001$ , adjusted  $R^2 = .37$ ). However, within a multivariate regression model controlling for sleep problems (**Figure 13**) the relationship between Avoidant coping and carer distress ceased to be significant ( $B = -.393$ ,  $t = -1.31$ ,  $p > .05$ , adjusted  $R^2 = .37$ ).

**Figure 13: Spearman's correlations between carer burden, sleep and distress**





## **7.6 Discussion**

### ***Rates of EE and its indices***

The rate of high EE observed in this total sample (N=78, 26%) was lower than that obtained in some studies conducted in first-episode samples in the UK (*e.g Patterson et al., 2005: 60%; Raune et al., 2004: 44%*). However, more consistent rates have been observed within mixed samples of first-episode and longer-term carers of individuals with psychosis (*Onwumere et al., 2009 and Kuipers et al., 2006b: 36%*). Speculation on the contributing factors to this finding might suggest a role for regional socio-demographics or the positive influence of established early intervention services. Observationally, a considerable proportion of the participating carers from the North East London boroughs were lower-income, two-parent families with established social support systems. Although early studies of EE examined rates of high EE between rural and urban areas in Chandigarh, India for example (*Wig et al., 1987b*), there are no published studies which have examined the influence of urbanicity or socio-economic factors in predicting prevalence of high EE versus low EE families in the UK. Additionally, this study was conducted almost ten years on from Patterson et al. (2005) and Raune et al. (2004); during which time early intervention teams and support services for families have developed at least partially, with an intended impact on families' abilities to cope. All eligible families registered with early intervention services were approached about the study, however it is possible that individuals who were experiencing more difficulties in coping with caregiving may have been less likely to take part. Furthermore, the sample consisted of a considerably lower proportion of white British carers than other studies. BA\_BAC carers constituted 53% of the sample and reported lower rates of high EE than WB carers in this study. The rate of high EE observed in the WB group (35%) was consistent with reports from samples with a majority (84%) of WB families (*Onwumere et al., 2009*).

Drawing direct comparisons between the rates of high EE obtained in samples from different countries should be done with caution due to differences in experimental design and sample

characteristics. However, within this study the groups did not differ significantly on any sociodemographic variables, nor in service user characteristics, and yet a sizeable difference in the rates of high EE was reported across the groups, that would only be observed by chance or error seven times in every hundred. This is consistent with other studies that have reported differential rates of high EE and its indices in different samples which they have attributed to ethnicity (e.g. *Lloyd et al., 2012; Lopez et al., 2009*), but not all (*Hoste et al., 2012; Hashemi & Cochrane, 1999*). In support of one of the primary hypotheses, BA\_BAC carers also reported significantly higher levels of warmth in this sample. In addition, fewer BA\_BAC carer participants were rated as high EOI by comparison to WB carers.

#### ***A predictive role for Warmth?***

In the early development studies of EE that examined the predictive utility of the indices, Brown and colleagues (1972) reported a curvilinear association between warmth and relapse after 9 months. This finding has since been observed in other samples (*Breitborde et al., 2007*). From a research point of view, less attention was paid to the predictive utility of warmth than the negative indices as a result of their correlation. At low levels, warmth was associated with high criticism and at higher levels it was associated with high EOI (*Brown et al., 1972*). From a clinical point of view, the means by which to help modulate levels of affection in a relationship were perhaps also less immediate than those available to intervene in cases of highly critical interactions and intrusive or overprotective behaviours. Yet there are more recent studies that have recorded an independent predictive effect for warmth (*O'Brien et al., 2006; Ivanovic et al., 1994, Bebbington & Kuipers, 1994*). High warmth, even in the presence of high EE, has been shown to predict fewer readmissions at follow-up than low warmth in the presence of high EE (*Bertrando et al., 1992*). Given the cross-sectional design of the present study, the results do not contribute to the evidence-base surrounding the predictive utility of warmth. However, they raise the issue of the potential differential importance of warmth in interpersonal relationships in families from different ethnic backgrounds. Higher levels of interpersonal warmth have been proposed to be

normative in certain cultures (*e.g in Mexican American families, Lopez et al., 2009*). An ethnicity-by-warmth interaction effect has also been reported in the prediction of relapse elsewhere (Lopez et al., 2004). In a series of logistic regressions Lopez and colleagues (2004) demonstrated that a one-unit decrease in warmth increased the odds of relapsing by 5 fold in Mexican American carers of individuals with schizophrenia compared to Anglo American carers.

***Ethnic differences in perceived burden and appraisals of caregiving***

Overall, there were no significant differences in positive or negative appraisals of caregiving made by carers from different ethnic groups. The second primary hypothesis, that individuals from certain minority ethnic backgrounds would be expected to report more positive appraisals of caregiving, may be observable in qualitative analyses of smaller groups (Lawrence et al., 2008). However, with a larger sample size and employing quantitative measurement instruments this finding was not replicated in the present study.

In the combined sample, levels of self-reported burden or negative appraisals of caregiving were high (mean ECI-neg score = 84.6, s.d = 39.8, max range = 0-208). This is consistent with the findings of a comparative study of 124 carers of individuals engaged with early episode services in London in which 61% of the sample self-identified as white British and 33% as black African or Caribbean (Boydell et al., 2013). The moderate proportion of carer-participants reporting clinical levels of depressive symptomatology in this sample (around a third) is also consistent with previous estimates (Sha et al., 2010; Kuipers et al., 2010, Magana et al., 2007). Given that this is a first episode sample of carers, the results suggest that the negative impact of the caregiving role is not delayed, as found previously (Lowenstein et al., 2010; Raune et al., 2004; Addington et al., 2003). Negative appraisals of caregiving were also the strongest correlate of critical comments in carers in the total sample.

***Ethnic differences in correlates of perceived burden/negative appraisals of caregiving***

Further exploratory comparisons of correlates of perceived burden or negative appraisals of caregiving revealed ethnic differences. Firstly, negative appraisals of caregiving were less strongly associated with distress (depressive symptoms, anxiety, sleep disturbances) in BA\_BAC carers than in WB carers. The sample size did not permit differences in zero-order correlations to be tested for their statistical significance. However, speculation on the results might imply greater resilience in the BA\_BAC group (*Utsey et al., 2007*). Alternatively the measures selected to examine carer outcomes may not fully capture the experience of distress across cultural groups. Outcome measure selection and standardisation in carer research is an acknowledged difficulty (*Harvey et al., 2008*). Secondly, the secondary hypothesis that a stronger relationship would be observed between carer burden and EE in WB as opposed to BA\_BAC carers was partially supported. Higher burden was less strongly correlated with critical comments in BA\_BAC carers by contrast to WB carers. In addition, higher burden did not correlate with overall EE for BA\_BAC carers but was negatively associated with warmth. This again suggests that the warmth index of EE may be a principle indicator of the impact of distress on relationship quality in some cultures.

***Ethnic differences in illness beliefs***

A higher frequency of white British carers cited genes as the principal cause for their relative's difficulties, whereas BA\_BAC carers more frequently cited psychosocial causes of illness. This finding supports the third primary hypothesis that BA\_BAC carers would be more likely to endorse external illness causes. Yet this difference did not influence the respective levels of controllability ascribed to patients for their symptoms, nor the expectations of cure.

Notably, in the combined first episode sample, carer perceptions of service user controllability over their symptoms was associated with less distress and lower levels of criticism. This is in contrast to previous research which has documented an association between control attributions and blame in relatives (*Barrowclough et al., 1994*), as well as

distress (*Onwumere et al., 2008*). It is possible that at this early stage perceived control over illness may be an index of service user health and hope for recovery. Some studies have investigated the relationship between presumed genetic causes of illness and self-blame in families of individuals with psychosis, with conflicting results as to whether genetic representations of illness are related to guilt amongst parental carers (*Callard et al., 2012*). Future studies might consider the interactions between beliefs about the causes of illness, guilt and EOI in carers, given the higher rate of EOI behaviours in this WB sample.

However, greater endorsement of psychosocial illness causes by BA\_BAC carers does not necessarily implicate differing explanatory models of illness across ethnicities. BA\_BAC service users may actually have endured more adverse life events that contribute to the development of illness than WB service users. This was not assessed in the present study, yet many of the psychosocial causes of illness noted by BA\_BAC carer-participants were particular to immigrant families, including immigration problems, specific employment issues and family separation. This hypothesis - that a greater frequency of adverse life events contributes to increased rates of psychosis in ethnic minority groups - has however been disputed by other studies. Cooper and colleagues (2008) and Gilvarry and colleagues (1999) for example did not find a significant difference in the number of adverse life events reported across ethnic groups. By contrast, Morgan et al. (2007) documented higher rates of separation from a parent before the age of 16 in black Caribbean controls by comparison to white British controls. Early separation from a parent was associated with a two-to-three fold increased risk of psychosis across both ethnic groups.

From a clinical perspective, the results confirm the need to consider the contribution that culturally-specific stressful life events make to the development of illness, and to people's conceptualisations of disorder. Qualitative responses from carers also suggested that specific life events may confer differential levels of stress within a cultural or religious context, for example, sexual identity concerns. The reported difference in the expected timeline of illness across the ethnic groups (BA\_BAC carers predicted a shorter illness duration) might also

suggest that different strategies for different ethnic groups might be needed to enable timely access to accurate information about psychosis.

### ***Religious coping***

Despite the majority of WB carers reporting a religious affiliation, carer-participants in this sample were significantly less likely to use religious coping strategies than BA\_BAC carers. This finding supports theories that acknowledge the distinct role that religion makes to the coping process over and above other religious beliefs or practices (*Pargament et al., 2011*). The items in the COPE scale however are limited and they fail to distinguish between potentially ‘adaptive’ and ‘maladaptive’ religious coping. For example, in patients religion is recognised as both a risk and protective factor that can shape the representation of psychotic symptoms both positively and negatively (*Cottam et al., 2011*), as well as aid recovery (*Gearing et al., 2011*). Within this carer sample, the results suggest that positive religious coping may predict low EE, as found in previous studies (*Wasserman et al., 2013; Weisman et al., 2003*). Furthermore, they suggest cognitive mechanisms that might partially contribute to the effect of religious coping, including positive reappraisal, active and planning coping.

### ***Sleep disturbances***

The exploratory analyses additionally make a contribution to the evidence suggesting that sleep disturbances may be a more prevalent and complex issue in carers than in the general population (*Rowe et al., 2008*). There is a growing evidence base on sleep problems in carers (*Kotronoulas et al., 2012; Lee & Thomas, 2011*), with estimates that up to two-thirds of carers may suffer from significant difficulties sleeping (*McCurry et al., 2007*). Yet there are very few studies that report on sleep quality in carers of individuals with psychosis (*Kim & Rose, 2011*), despite the prevalence of disturbed sleep and insomnia in patients themselves (*Freeman et al., 2012; Cohrs, 2008; Levin & Fireman, 2002*). In an exception to this, Wong (2000) and colleagues recorded qualitative reports of sleep disturbances in carers of individuals with schizophrenia in Hong Kong and noted that ‘worry’ over the care of their relative was a frequent explanation for reduced sleep quality. Unprompted, one fifth of the

present sample also noted worries as an explanation for lack of sleep. Sleep was reported to partially mediate the relationship between negative appraisals of caregiving and mental health. This concurs with the findings of Phillips et al. (2009). Avoidant coping also ceased to be significant in predicting mental distress, as measured by the SF-36 mental health subscale in this sample, once sleep was included in the regression analysis.

However, the meaning of the role of sleep in caregiving distress is not revealed by these findings. Firstly, regardless of the objective quality of sleep, individuals under stress will regularly feel that their sleep is suffering. The validity of self-report measures to quantify sleep independently from other negative appraisals of caregiving and stress is therefore questionable. Secondly, interpretation of the results is restricted by the cross-sectional design of the study. No causal inference can be inferred. Sleep may be disturbed directly by the night time awakenings of unwell relatives, as in conditions such as dementia, however it is likely that negative appraisals of caregiving and sleep affect one another in a bi-directional relationship. This is consistent with previous findings that show poor sleep is associated with increased anxiety and depression, and in some cases has been shown to be predictive of symptomatology (Cuijpers, 2005; Spira et al., 2005).

The correlations observed between avoidant coping, sleep and distress in this sample are more difficult to interpret. Poor sleep may encourage a more avoidant coping style, via low mood and lack of motivation. However, given the frequency with which worries are reported as the reason for lack of sleep, a strong case emerges for the hypothesis that an avoidant coping style, which leaves issues unresolved during waking hours, also results in greater night-time activity in an attempt to process concerns. Behavioural interventions that target carers' sleep quality may help moderate mood. However, the findings support the inclusion of cognitive components in interventions to address worries and coping.

The study also therefore raises the need to incorporate sleep interventions into work with families and carers in psychosis. Evidence exists to support their efficacy in other carer

groups. Using a brief behavioural intervention incorporating psychoeducation, behavioural methods of reducing the impact of patient sleep disruptions, sleep compression and relaxation techniques in dementia carers, McCurry et al. (2007) reported an improvement in sleep in carers that was maintained at 3-month follow-up. Similarly, using a cognitive intervention with carers of individuals with cancer, Carter (2006) reported an improvement in sleep and depressive symptomatology in participants.

***Limitations: ethnicity as a proxy for culture***

The heterogeneity of cultures and ethnic identities incorporated in the respective ethnic groupings of carers is a central limitation for the research project. Yet it is one that is faced by many studies attempting to examine cultural influences. The demography of South London is not conducive to the discrete distinctions between migrant groups adopted in other studies (*e.g Lopez et al., 2004*). The BA\_BAC group for example comprised carer-participants of first, second and third-generation immigration status, from African and Caribbean origins. It would potentially have been possible to segregate this grouping but at the expense of sample size and statistical power. The decision was taken during study design to prioritise examining hypotheses in a large enough sample that any ethnic differences observed might indicate crude but systematic and statistically robust variation potentially of greater relevance to the process of adapting established clinical interventions than differences observed in smaller ethnic group samples that might not be generalisable.

As an alternative approach, an extensive review of the literature was conducted in search of a suitable acculturation scale for the study. The multidimensional Culture and Identity Interview Schedule (*Bhugra et al., 2010*) was the only scale to have been validated within the ethnic groups in question. However, this was too lengthy an interview scale for the present purposes and there was no clear theoretical rationale for the relevance of the items to caregiving processes. Given the intended sample, it was further assumed that the study would violate the criteria outlined by Hunt and colleagues (2004) that should be satisfied in



justifying comparisons of cultural differences within the context of an assumed acculturation process. The study therefore employed self-identified ethnic group status as a proxy to explore presumed cultural differences. Arguably this is a requisite first step in developing an evidence base relating to variations in responses to caregiving observed clinically, that may be attributed to cultural background. However, crucially it does not permit correlations to be drawn between outcomes and any specific elements of cultural orientation or ‘cultural mechanisms.’ The question therefore remains as to what unites the individuals comprising each group that drives observed differences (e.g religion, outsider status, perceived discrimination, social support). Nevertheless, the detailed analysis of potentially confounding factors, together with the fact that BA\_BAC and WB carers in this sample were equivalent when rated on socio-economic characteristics, negates the hypothesis that ethnic minority status is merely a marker of social disadvantage. Scores on the Multi-Ethnic Identity Measure showed that both groups expressed an affiliation with their ethnicity, with BA\_BAC carers showing a stronger affiliation than WB carers.

***Limitations: recruitment***

Challenges in recruitment further motivated a study design based on broad ethnic categories. The process of recruiting carers for research was complicated by a number of contributing factors:

- service users declined to share study details with their carers or to consent for them to participate.
- carers were frequently dealing with high levels of burden, including additional employment and family commitments, as well as their own health concerns, preventing study involvement.
- individuals did not necessarily recognise their activities as constituting 'caregiving' despite providing vital recovery support for relatives.
- current ethical procedures stipulate that first contact with potential participants must come directly from clinical teams, who were under resourced to provide this support in addition to regular services.

The observed recruitment rate of 1 in 4 families reflects these challenges and is consistent with other studies. The study remains amongst the largest and most ethnically diverse carer samples investigated in the UK. In addition, this recruitment rate would be much higher if it represented those individuals who decided to participate following direct contact with the study team. A high proportion of families recommended by care co-ordinators to receive initial information were subsequently excluded because they did not meet the inclusion criteria. For example, illness characteristics or face to face contact time with service users. The lower conversion rate in the BA\_BAC group may also be partially explained by exclusion criteria specifically affecting the ability of ethnic minority carers to participate, including sufficient proficiency in English and self-identified ethnicity. Additionally and anecdotally, families from ethnic minority backgrounds were noted as experiencing additional barriers to participation in the study including pending immigration issues, carer absences abroad and relatives currently in inpatient care. Possible sources of recruitment bias that must be considered in interpreting the representativeness of the recruited sample include recommendations made by care co-ordinators of possible participants. Whilst the recruitment process endeavoured to be as comprehensive as possible, information about the study was inevitably not issued to every service user who might have a carer eligible to participate but rather to individuals judged appropriate to be approached by clinical teams based on inclusion criteria but also, inevitably, on wellness, stability and potential likelihood to be interested in the project.

***Limitations: experimental design***

The significance of the findings in the study must be interpreted within the context of the reduced sensitivity of non-parametric statistical testing procedures where these were applied. Service user characteristics, including length of illness and number of admissions depended on carer self-report for those cases in which service-users themselves did not participate in the overall study. Study 2 therefore lacked a more comprehensive measure of clinical symptomatology. However, the evidence base supporting an association between service-

user symptoms and carer outcomes is conflicted, with studies suggesting chronicity is more relevant than type of symptom (*Rafyah et al., 2011, Awad & Vorunganti, 2008*) and that carer appraisals of illness are of greater importance to distress levels than the characteristics of illness itself (*Martens & Addington, 2001*). Moreover, although the experiences of each family will vary greatly, the sample was restricted to carers of individuals registered with first-episode services who will all have had to contend with a recent period of acute symptoms. The sensitivity of some of the measures may also have been compromised by the selection of shortened-versions in which certain subscales are assessed with one or two items.

### ***Implications***

In this adequately-powered sample size, using the most rigorous assessment of EE, the study reported marked differences in the rate of high EE and expression of its indices in white British compared with black African, Caribbean and black British carers. As with previous research this leads to consideration of what these differences mean. The findings would seem to contradict the suggestion that socio-demographics, illness characteristics or individual differences might explain the discrepancy. The difference might be a ratings issue resulting from miscategorisation of responses across different ethnic groups. However, both CFI raters were trained to criteria. These criteria include accounting for cultural norms of families in ratings. Furthermore, the raters were representative of the ethnic groups included in the study. The results also suggest a potentially more important role for warmth in different cultures. Future work might reconsider the relationship between warmth and the other indices of EE and their utility in predicting relapse for non-Western service users. Ultimately questions about the cross-cultural validity of EE and the predictive utility of its indices across cultural groups can only be answered by looking at psychopathological outcomes in service users from different ethnic backgrounds in appropriately powered, follow-up studies. However, looking at experiences of EE from the patient's perspective offers an alternative way in which to analyse whether the behaviours and attitudes that

comprise EE in established CFI ratings are experienced as distressing by patients from different cultural backgrounds.

The results could have implications for Family Interventions in psychosis that aim to reduce criticism and emotional overinvolvement in caregiving relationships by working with appraisals of caregiving, illness beliefs and coping, improving warmth indirectly. Further exploration of cognitive correlates of warmth would be required in different ethnic groups in order to identify whether mechanisms exist that could form the basis of interventions that target warmth directly. Coping style for example emerged as an important correlate of distress in BA\_BAC caregivers. In addition, the integration of sleep interventions for carers of individuals with psychosis presents a new development that may help improve carers' mood, capacity to cope and ability to engage with clinical services. The findings also support previous studies which suggest that interventions targeting carers' attributions of patient' control over their symptoms must be sufficiently sensitive to ensure, for example, that diminished perceived control does not lead to ascription of a 'sick role' that threatens autonomy and self-esteem (*Renshaw, 2006*). This study suggests that in the early stages of illness attributions of control may be associated with less distress in carers. However, it is not clear how this might be experienced by patients. It could be associated with less blaming attitudes in carers, yet it could also be perceived by patients as greater pressure to ensure a speedy recovery. Finally, the study also substantiates the importance of supporting low EE carers pre-emptively, highlighted by Kuipers and colleagues in their cognitive model of caregiving (2010). Although a lower rate of high EE was recorded within the BA\_BAC carer sample, no significant differences were observed in self reports of carer burden or levels of distress by comparison to WB carers.

## **8. Study 3: Measuring perceived Expressed Emotion in first-episode psychosis**

### **8.1 Study aims and hypotheses**

A third exploratory study aimed to evaluate the construct validity of an aggregated scale of perceived expressed emotion, completed by service-users. As explained in Chapter 5, emerging evidence has demonstrated a link between perceptions of criticism and clinical outcomes across a range of disorders and in at-risk groups (*Schlosser et al., 2010; Renshaw et al., 2008; Thompson et al., 1995*). Researchers have acknowledged a requirement for shortened measures of the quality of caregiving relationships, as an alternative to the Camberwell Family Interview (CFI) (*Hooley & Parker, 2006*). Several studies also suggest that service users' perceptions may be better predictors of outcomes across ethnic groups in which CFI 'norms' are not established (*Rosenfarb et al., 2006a; Weisman et al., 2006; Thompson et al., 1995*). A patient scale capturing each of the indices of EE could not be identified in the literature. The main aim of the study was therefore to compile a comprehensive self-report scale of perceived expressed emotion, short enough to be applied in a clinical setting. In addition, the study intended to examine the reliability and convergent validity of the items in an early psychosis group, given documented deficits in emotion recognition and processing in patients (*Chan et al., 2010*). It was hypothesised that service-user perceived criticism would be associated with CFI-derived criticism ratings (*Cutting et al., 2006*).

### **8.2 Methodology**

#### ***Ethics and recruitment***

Ethics approval was granted by the Berkshire Research Ethics Committee on 27<sup>th</sup> October 2010; reference number **10/H0505/79, Appendix 2**. To enable recruitment through clinical teams further permissions and site approvals were obtained from the following NHS Trust Research and Development Offices: East London (**ReDA ref: JB1210/1**), North London, Oxleas and South London and the Maudsley.

Along with study 2, recruitment took place during the period April 2011 – Feb 2013 via Early Intervention in Psychosis teams in ten London Boroughs with high ethnic minority populations: Barking and Dagenham, Bromley, Croydon, Havering, Lewisham, Bexley, Redbridge, Southwark, Tower Hamlets and Waltham Forest. Carer-participants were a mixed-ethnicity sub-sample of individuals who agreed to take part in Study 2, whose (service user) relatives also consented to the study. With approximately 280 families approached, recruitment rates were approximately 1 in 6 service users by comparison to 1 in 4 carers. However, in over 50% of cases in which carers agreed to participate, so also did service users. Recruitment and consenting procedures were as detailed for Study 2, **section 7.2.**

### *Composition of the Scale*

A systematic review was conducted in accordance with PRISMA guidelines (*Moher et al., 2009*) to identify studies that 1) reported on the measurement of patient perceptions of expressed emotion and its validity as a research construct and/or 2) investigated the relationship between patient perceptions of any index of Expressed Emotion and clinical outcomes across disorders. The following databases were searched in August 2010: Embase, Medline and PsychINFO through OVIDSP and Pubmed. The database search was restricted to English language papers or papers with an abstract in English. All published studies from database inception to date were considered. Search keywords were divided into groups: 1) “perceive\*”, “patient perception\*” 2) “criticism\*”, “negative attitude\*”, “emotional”, “overinvolve\*”, “overprotect\*”, “intrusive”, “involvement\*”, “expressed emotion\*”, “warmth” 3) “measure\*”, “scale\*”, “instrument\*”. Terms from different groups were combined to form title search strings. MeSH terms, where available, were combined and explored. Citations from identified studies and review articles were examined to identify additional relevant studies.

Titles from 456 papers were examined; duplicates and foreign language papers were excluded. A total of 115 papers were selected for review. Key papers published in the last 25 years were discussed in chapter 5 and are shown in **Table 3, p. 184**. The following criteria were used to guide item selection: previous use in a psychosis or at-risk sample, items or scales conceptually based on the EE construct, data available on validation against the CFI, and appropriate length for clinical application.

As the only items satisfying these criteria, this led to the selection of four items from the Perceived Criticism and Emotional Involvement Scale (*Cutting et al., 2006*), previously used within a schizophrenia sample and including Hooley and Teasdale's (1989) single perceived criticism question. These were combined with warmth items (four) selected from the Brief Dyadic Scale of Expressed Emotion (*BDSEE; Medina-Pradas et al., 2011*) to comprise the main indices of EE. Details on the development of the BDSEE (within a sample of individuals with eating disorders) were published in June 2011, after the present study had commenced. Prior to this no warmth items were identifiable in the literature. The subsequent inclusion of these items was approved by the Berkshire Research Ethics Committee as a substantial amendment (**Appendix 2**). Individuals who had already consented and taken part in the study (n=16) were re-contacted, within at most 10 months, to recomplete the full scale. Three people could not be reached. At the time of re-administration individuals were asked whether there had been any change to their living arrangements or average weekly face-to-face contact with their main carer, as well as whether they had experienced any further psychiatric admissions or episodes of illness.

### ***Measures***

#### ***Caregiving Relationships Questionnaire (CRQ)***

The aggregated scale completed by patient participants is shown, along with other measures, within **Appendix 6**, entitled Caregiving Relationships Questionnaire (**CRQ**). Items were

scored on a 0-10 scale. Sum scores were calculated for the EOI (**CRQ\_EOI**) and warmth dimensions (**CRQ\_WA**).

To assess concurrent validity, or the extent to which service users were perceiving ‘actual’ distress and emotional responses from caregivers in their interactions, the new CRQ scale was compared with the Camberwell Family Interview (*CFI, Vaughn & Leff, 1976a*): an objectively-rated measure of the quality of caregiving relationships, as well as selected dimensions from self-report carer outcome measures of burden and appraisals of caregiving: the Experiences of Caregiving Inventory (*ECI, Szmulker et al., 1996*) and Family Attitude Scale (*FAS, Kavanagh et al., 1997*). Details on the ECI and CFI are given in above section **7.2**. The FAS is described below. Additionally, in order to examine the validity of patient perceptions of Expressed Emotion, as distinct from the effects of illness or individual sensitivities to interpersonal interactions, measures of symptomatology (*Brief Psychiatric Ratings Scale – expanded, BPRS, Lukoff et al., 1986*), sensitivity to arousal (*Arousal Predisposition Scale, APS, Coren, 1988*), general emotional reactivity (*Emotional Reactivity Scale, ERS, Docherty et al., 2009*), and core schematic beliefs about others (*Brief Core Schema Scale, BCSS, Fowler et al., 2006*) were completed by service users and controlled for in correlation analyses between objectively-rated expressed emotion and perceived expressed emotion. Details on these service user measures are also described below and shown in full in **Appendix 6**.



**Table 3: Systematic review of studies of perceived expressed emotion: key studies**

Reference	Sample characteristics	Instruments	Predictive validity	Concurrent validity	Conclusions
Scott et al., 2012	33 bipolar patient & sig. other dyads	PCM - 10 point anchored Perceived Sensitivity – 10 point anchored. Treatment adherence Knowledge of disorder and treatment	12-month f/u. At least 1 x hospitalisation for BD relapse.	PC associated with PS, treatment adherence and KADI	PC associated $r = .31$ , $p = 0.032$ with BD relapse after control confounds
Salokangas et al., 2012	55 At Risk outpatients from the European Prediction of Psychosis Study	Negative Attitude of others (NAO) - single item 3 choice response from the PROD screen (intent of others)	9, 18 and 48 months after baseline Transition to psychosis TTP: above threshold symptoms for >1 week	-	NAO at baseline significantly ( $P = 0.007$ ) predicted TTP.
Möller-Leimkühler & Wiesheu, 2012	102 key relatives of adult schizophrenia population mean duration illness 18 years, most <15 pw contact	German Family Questionnaire to assess EE FEF (in German) to assess perceived EE Family burden questionnaire	-	Regression analyses looking at predictors of burden, perceived EE not included.	Good concordance between carers overall EE assessed by FEF and assessed by perceived EE.
Medina-Pradas et al., 2011	77 eating disorder and 'key relative'; 'most contact'.	Brief Dyadic Scale of Expressed Emotion (BDSEE). 3 scales, four items each, measuring EOI, warmth and criticism, 10-point scale.	-	Associations with CFI and additional measures e.g parental bonding instrument	Significant association between BDSEE criticism and CFI criticism: $r = .31$ for $p < .01$ And EOI dimensions: $r = .37$ for $p < .01$ . Warmth correct direction, n.s.
Peterson & Smith, 2011	118 marital couples, depressed and non-depressed	PCM – adapted 5 response format Relationship attributions measure	-	Associations with negative causal and responsibility attributions for spousal behaviour	Sig. association PC & attributions; $r = .51$ , $p < .001$
Guada et al., 2011	88 outpatient schizophrenia and family member representative (contact over preceding 60 days )	PCM – 10 point anchored Role functioning scale Colorado symptom inventory	-	Regressions with social functioning, contact and symptomatology	Symptomatology predicted PC in regression model $p = .001$ , $t = 3.37$ , $b = .08$ .
Hale et al., 2011	285 adolescents from community sample and their parents	Level of Expressed emotion scale, extended to include perceived constructive criticism	4 year, 3 wave follow-up Depressive symptoms Delinquency behaviours Aggressive behaviours	-	Perceived lack of emotional support, intrusiveness, irritability, crit. & const. crit. predict symptoms.

**Table 3: Systematic review of studies of perceived expressed emotion: key studies**

Möller-Leimkühler & Jandl., 2011	At baseline: 16 first hospitalised schizophrenia patients and 25 key relatives 15hpw, F2F. 34 depressed patients and 45 key relatives	German Fragebogen zur Erfassung der Familienatmosphäre (FEF) Family Atmosphere as proxy for perceived criticism FMSS Family Burden Questionnaire	Yearly follow-up over 3 years PC prediction of carer burden	Associations with expressed criticism measured by FMSS	Consistent associations between FMSS_CRIT and PC_CRIT at each point of assessment, except at 3-year follow-up. Expressed criticism, followed by perceived resignation better predictors of burden at follow-up than perceived criticism.
Nelis et al., 2011	651 Dutch adolescents	60 item Level Expressed Emotion Scale: subscales are Intrusiveness, Negative Attitude, Tolerance/expectation and Emotional Response.	Exploratory factor analysis of LEE, suggesting a 3 factor structure and reduction to 34 items. Some validation with symptom scales.		
Docherty et al., 2011	27 stable outpatients with schizophrenia and 'most influential other.' at least one F2F	CFI PCM – 10 point Cut-off scores that yielded same proportion of individuals in high versus low to delineate the PCM cut off. PANSS	9 month f-up.	PCM significantly related to high vs low CFI criticism ratings, $t_{26} = 2.29$ , $P = .03$	Anxiety interacts with CFI-EE to predict increase in symptoms Objectively measured levels of criticism were more predictive than patient-rated levels of criticism. High and Low PC had same mean at time point 1.
Renshaw et al., 2010	545 undergraduate students	PCM – 10 point PC-T – two items differentiating between perceived constructive criticism and perceived hostile criticism BAI, BDI, Relationship Assessment Scale	-	Study 1 no association between general PC and anxiety and depression but this was significant in study 2. Associations between different forms of criticism assessed.	Perceptions of hostile and nonhostile criticism were negatively correlated. General ratings of PC were unrelated to perceptions of nonhostile criticism, aside from in those with low level depressive symptoms. PC positively related to perceptions of hostile crit.

**Table 3: Systematic review of studies of perceived expressed emotion: key studies**

Chambless et al., 2010	50 community couples 70 patients OCD/panic plus partner or family member	PCM – global – 10 point PC - interaction-specific - after a 10-min problem-solving interaction (study 1 only) Negative attributions from problem solving interaction, internal, controllable.	-	PC and negative attributions.	In both studies higher scores on negative attributions were related to higher perceived criticism ratings
Chien & Chan et al., 2010	405 outpatients with psychotic disorders and a family member	52 item Chinese version of the LEE; Specific Level of Functioning Scale for patients; BPRS; Family Assessment Device	Symptom changes over 6 months	Chinese Family Assessment Device, some comparison with family functioning	LEE showed small to medium effect sizes for detecting symptom changes
Di Paolo et al., 2010	63 patients anorexia nervosa, bulimia and binge eating disorder 'Most influential person in life', number of contacts per week, binary split into $\leq 35$ and $\geq 35$ hpw.	Italian translation of the LEE	-	Correlations between the LEE and Eating Disorder Questionnaire, Emotional Eating Scale, Binge Eating Scale	Several significant correlations between LEE subscales and measures of eating disorder pathology.
Schlosser et al., 2010	63 At risk individuals and 'family member' no contact specified	PCM – 10 point Study adaptation for patient perceived warmth and for family perceived criticism and warmth. Items not given. CFI Symptoms scales	6 month follow up Prediction of severity of prodromal symptoms and functioning. Comparison of interview-based (CFI) versus self report ratings of the family environment (PCM)	Patient perceived crit. non sig but negatively correlated with CFI crit & positively correlated with CFI warmth? Patient Perceived Warmth correlated with CFI warmth. Family member's perception of their own warmth negatively correlated with CFI crit and positively correlate with CFI warmth.	Patient rated criticism and CFI criticism predicted symptom increase over time but not functioning. Patient's self-report ratings of criticism had stronger predictive power. EOI as protective factor when exhibited at moderate levels (3) AND in the presence of warmth. CFI EOIXWARMTH predicts functioning over time
Peterson & Smith, 2010	118 couples and spouses	PCM – 5 point response format 10 minute problem solving interaction. Criticism rated and valence given, positive or negative Interaction also objectively rated	-	General PCM, interaction specific video rated for P. constructive & destructive crit. Also objective rating.	PC related to destructive rather than constructive criticism from video.

**Table 3: Systematic review of studies of perceived expressed emotion: key studies**

Lue et al., 2010	1599 Taiwanese students	Family Expressed Emotion and Involvement Scale (FEIS)	-	-	PC associated with student depression and related indirectly to antisocial behaviour.
Bolton et al., 2009	28 clinic-referred adolescents and their mothers participated (excluded if not living together for > 12 months)	FMSS Perceived parental criticism (Brewin 1996) Self Perception Scale from Global Self Worth Self criticism scale, Children's Depression Inventory	-	No correlations between investigator rated criticism and adolescent perceived criticism	Perceived maternal criticism predicts self-crit ( $\beta = 1.29, t = 2.04, p = .05$ ). Both perceived maternal criti ( $\beta = .072, t = 3.3, p = .03$ ) and self-crit ( $\beta = .0027, t = 3.19, p = .004$ ) predict dep. symp. Perceptions of parenting rather than investigator ratings were most closely related to self-evaluation and depression
Chambless & Blake, 2009	1. 50 community couples 2. 70 patients OCD/panic plus partner or family member	1. PCM and interaction specific perceived criticism rated by both parties in the couple 2. PCM and destructive PC rated by observers from problem solving interaction (KPI) Psychopathology, marital satisfaction	-	Correlations between couples ratings of PC of each other. Correlations between OCD patients PC and CFI_crit and observer rated destructive criticism	Moderate and sig. correlations between couples on PCM. Large correlations on interaction specific PC. PC did not correlate with CFI-Crit. PC correlated with destructive crit
Gauda et al., 2009	88 African American outpatients with schizophrenia	PCM Measure of symptomatology and psychosocial functioning	-	-	PC associated with symptomatology by not psychosocial functioning.
Salokangas et al., 2009	790 outpatients total. Analyses at three sample levels PROD screen, 'vulnerable' to psychosis (219) and currently At Risk (55).	PROD screen, Bonn Scale for Prodromal symptoms and SIPs, patient written descriptions of symptoms as a measure of vulnerability to psychosis Measures of functioning and interpersonal relationships Negative Attitude of Others	-	Negative attitude of others correlated with symptom, functioning and interpersonal relationships measures.	Vulnerability to psychosis associated with all measures. Current risk of psychosis associated solely with perceived NAO. NAO associated with feelings of reference at vulnerable and at risk levels.

**Table 3: Systematic review of studies of perceived expressed emotion: key studies**

Gerlsma et al., 2009	34 general community couples, distressed vs happy	PCM – 4 response format Criticism subscale of Dutch LEE (3 factor structure) FMSS Interpersonal Problem Solving Inventory for marital problems BDI	-	<i>Associations between individual and partners perceived criticism within couples</i> $r = 0.53, P < 0.01$ for LEE-PC; $r = 0.43, P < 0.01$ for SIPC). Single items PC stronger association with FMSS crit than LEE-C	Multilevel analyses suggested that PC was associated with both partners' expressions of criticism, and the perceiver's depressive and marital complaints.
Onwumere et al., 2009	67 carer-patient dyads, long and short term schizophrenia	PCM, adapted 6 point response format CFI	-	Patient and carer characteristics CFI	PC associated with general psychopathology, but not overall levels of +ve and -ve symptoms; lower levels of social functioning, higher levels of negative affect, negative schema. CFI-EE, hostility and criticism associated with PC.
Renshaw, 2008	-	PCM	Review of PC predictive across disorders. 12 studies.	CFI	7/12 studies across disorders confirm predictive validity of PCM. Conflicting evidence on convergent validity. Taylor & Meeks (1996) & Tompson et al. (1995) = psychosis stud.
Cutting et al., 2006	32 patients w/ schizophrenia and 'influential other'	General sensitivity to criticism (STC) PCM – 10 point 4 P_EOI items same format Perceived Stress (PS)	-	Convergent validity between perceived crit and EOI and CFI crit and EOI and sensitivity to criticism; regression analyses to predict PC.	CFI_CC and PC: $R = .39, R^2 = .15, p < .05$ . Overall EE and PC: $.44, R^2 = .2, p < .01$ . EOI items n.s. but CFI_EOI related to PS.

**Table 3: Systematic review of studies of perceived expressed emotion: key studies**

Weisman et al., 2006	42 patient family dyads with schizophrenia	PC measured on a three point response format CFI	-	Examined concordance between perceived criticism and CFI-derived criticism	As predicted white and latino families PC & CFI crit correlated; $r = .50$ , $p < .05$ this was not true for black families $r = -.07$ , $p > .05$
Hooley & Parker, 2006	-	PCM, FMSS, Family Attitude Scale, LEE	Review article of evidence on predictive and convergent validity of 4 scales conceptually based on the EE construct; w/ validation data with CFI	-	-
Miklowitz et al., 2005	360 patients with bipolar disorder	10-point PC measure inc. additional items added by White et al. 1998 incorporating level of perceived distress.	Assessment of mood symptoms and days of recovery over a period of 12 months	-	Patient's perceptions of criticism not related to mood scores and % days well at follow-up but level to which they were upset by perceived criticism did. $F = 5.42$ , $df = 1, 872$ , $p = 0.02$
Bachman et al., 2005	-	PCM, FMSS, FEICS and German Family Atmosphere questionnaire (FEF)	-	A comparison of self rated instruments for perceived criticism w/ FMSS and between patient measures	Correlations in patient's assessment instruments was moderate to good. Patient's perspectives corresponded with relatives.
Yan et al., 2004	47 outpatients with bipolar disorder	PCM – 10 point response format Perceived negativity in social supports General Life Stress FMSS_EE	Relative predictive utility: depressive and manic symptomatology over 12 months	-	High EE predicted depressive but not manic symptoms. Perceived negativity from best friend predictive. PC trend in predicting manic recurrence $p < .06$ .

**Table 3: Systematic review of studies of perceived expressed emotion: key studies**

Van Humbeeck et al., 2002	-	PCM PPI LEE FEICS IRQ	Review of 11 alternative instruments to the CFI. Patient measures include Patient Perceptions of Family Relationships interview (PPI). Self-report: Level of Expressed Emotion scale (LEE); Family Emotional Over-involvement and Criticism Scale (FEICS). Influential Relationships Questionnaire (IRQ).	PCS predictive in a sample of individuals with depression. However, did not correlate with CFI derived criticism. Further studies required in schizophrenia samples.	-
Scazufca et al., 2001	43 patients after psychiatric hospitalisation w/ schizophrenia and family member	CFI PCM – 6 point Likert scale response format	-	Study of reliability and convergent validity of PC and CFI at baseline and 9 month f-up.	Reliability of PC was moderate to good. PC associated with CC and hostility at baseline $r=.43$ ; $p=.005$ ; at follow-up convergent validity w/ CFI_CC weaker $r=.28$ ; $p=.16$ . Symptoms not associated with PC at inclusion.
Tompson et al., 1995	81 patients with schizophrenia, maintained on low doses of neuroleptics, and key relatives.	Detailed Family Interview to assess patient's perspectives, Patient Perceptions of Family Interview (PPI); perceived criticism; nagging and EOI extracted from 9 subdomains. FMSS – EE	Psychotic symptoms exacerbation as measured by significant change scores on clustered items on the BPRS.	PPI responses associated with FMSS.	PC congruent with FMSS_CC, in all cases except ethnic minorities. EOI and nagging scales, not. PC predicted FMSS high EE status in 73% of cases. Patient PC predicted relapse 12 month f-up. High versus low contact hours strongly predictive of outcome in association with relationship variable. High PC/Low contact most predictive? No assoc. with symptoms.

**Table 3: Systematic review of studies of perceived expressed emotion: key studies**

Lebell et al., 1993	39 chronic schizophrenia outpatients and family members	Perceived Negative Attitude, 5 point Scale	Significant exacerbation of symptoms at 12 month follow-up	-	PC predictive of outcome. $\chi^2=8.29, P<0.004$
Shields et al., 1992	100 general outpatients, older adults	Family Emotional Involvement & Criticism Scale; PC scale and overall emotional involvement, intended to be analogues to CFI but not exactly.	-	Concurrent validity assessed by comparisons with Family Adaptability and Cohesion Scale and Interpersonal Support Scale.	PC has substantial bivariate correlation between depression & anxiety
Hooley & Teasdale, 1989	39 patients with unipolar depression and their spouses	PCM, CFI, Dyadic Adjustment Scale for marital, distress/satisfaction	9 month f-up; reported episode of depression with accompanying levels of symptoms to meet PSE criteria for depression.	Intercorrelations between PC, CFI_CC and marital satisfaction	All three variables indptly predictive of outcomes. PC alone accounted for greater variance in relapse rates than CFI and marital distress combined $r=.64$ $p<.001$ . PC associated with CFI-overall but not CFI_CC. PC independent of symptoms.
Cole & Kazarian, 1993, 1988	36 outpatients with schizophrenia	LEE; 60 items; total score and 4 subscales developed on the basis of high EE described by Vaughn & Leff (1981): intrusiveness, emotional response to patient's difficulties (e.g anger); negative attitude, low level of tolerance	Rehospitalisation at 1, 2 and 5 years.	Validated against the IRQ.	Moderate to strong positive intercorrelations between the scales. Overall LEE and IRQ moderate correlations. Overall LEE score predictive at 2 and 5 years. n.s at 1 year.
Warner & Atkinson, 1988	62 patients with schizophrenia	The Parental Bonding Instrument; ratings made on parental care and protection	12 month f-up.	-	Patient's who perceive parents positively tend to experience a milder course. Also reported relationship with contact. Patients in High contact and High risk based on low PBI scores more likely to experience exacerbation.



**Measures cont.**

**Family Attitude Scale (FAS)**

**Kavanagh et al., 1997**

The Family Attitude Scale (FAS) is a 30-item questionnaire which assesses negative feelings and thoughts, as well as perceived burden, reported by a relative in relation to a patient, over the past 4 weeks. Statements such as '*he is infuriating*' or '*he makes me feel drained*', are combined with reversed positive items, '*I feel very close to him*' (n=10) and are rated on a 5 point scale (4 - every day, 3 - most days, 2 - some days, 1 - very rarely, 0 - never). Scores range from 0-120. An initial series of 80 items was generated from clinician experience and in consultation with the EE literature. Correlation analyses resulted in the selection of 30 statements to form the present scale with high internal consistency ( $\alpha = 0.95$ ) but with the loss of items intended to measure EOI (Kavanagh et al., 1997). The FAS has therefore been recommended as a self-report alternative to the CFI in cases in which criticism ratings are of particular interest.

Validation studies report 76% correct classification of high and low EE ( $\chi^2(1)=13.64$ ,  $p < 0.001$ ) at an optimal threshold of ( $\geq 51$ ) in relatives of patients with psychosis (Kavanagh et al., 2008). High EE, criticism, is significantly correlated with a higher FAS score. However, a higher cut-off of ( $\geq 60$ ) is required for prediction of relapse. To date this has only reached significance in a first-episode group (Kavanagh et al., 2008). The FAS has also been associated with negative caregiving experiences as measured by the Experience of Caregiving Inventory, but this was restricted to maternal ratings (Kavanagh et al., 2008). The scale has been used in Japan and in Hong Kong with some evidence of efficacy in differentiating high and low EE groups (Arthur, 2002; Fujita et al., 2002). Cultural differences, more pronounced for fathers, have been reported, but only within early validation studies with student groups (Kavanagh et al., 1997).

**Brief Psychiatric Ratings Scale – expanded (BPRS)**

**Lukoff et al., 1986**

The BPRS is a structured interview with ratings scale that assesses symptoms of general psychopathology. The 24-item expanded version developed for use with outpatient

psychiatric populations was used in the study (Lukoff *et al.* 1986). Probe questions are provided for positive symptoms, including hallucinations and delusions; negative symptoms, reflecting emotional withdrawal and blunted affect; as well as depression and disorganisation. This four factor structure was obtained within a sample of recent onset schizophrenia patients (Van der Does *et al.*, 1993) although this varies across groups (Ventura *et al.*, 2000). Thirteen of the items are rated according to individual responses based on a preceding 2 week period. The remaining items are rated based on observations made during the interview. Anchor points are provided for each of the scales and answers are rated 1-7 based on severity. This is established according to weekly frequency, intensity and duration as well as impairment of functioning (Ventura *et al.*, 1993). The expanded BPRS has shown good inter-rater reliability over time for clinical-trained and lay interviewers (Roncone *et al.*, 1999).

***Arousal Predisposition Scale (APS)***

***Coren, 1988***

The **APS** is a 12-item scale that assesses general trait arousability. It provides a self-report measure of behavioural response to arousing stimuli (positive and negative) and offers a cost-effective alternative to more invasive physiological monitoring systems. Respondents indicate on a 5-point Likert scale [never, or almost never (0), seldom (1), occasionally (2), frequently (3) and always or almost always (4)] the degree to which an item characterises their responses e.g 'I startle easily', 'I am a calm person' (reversed) and 'I find my heart keeps beating fast for a while after I have been 'stirred up'. This scale has shown good internal consistency in patient groups,  $\alpha = .93$ , and controls = .89 (Coren & Mah, 1993). There is further evidence to suggest that it is a good predictor of physiological arousability (Dinzeo *et al.*, 2008).

***Emotional Reactivity Scale (ERS)***

***Docherty et al., 2009***

The **ERS** is a 13-item scale designed to assess emotional reactivity to a range of positive and negative sensory and social stimuli. Responses are scored on a 5-point Likert scale [never, or almost never (0); seldom (1), occasionally (2), frequently (3) and always or almost always

(4)] and include the items ‘*criticism upsets me*’, ‘*loud noises bother me*’ and ‘*I care whether people like me.*’ The ERS was created by Docherty and colleagues (2009) to fill a gap for a self report measure of general emotional reactivity that was comprehensible both to control groups and potentially cognitively impaired schizophrenic patients. Internal consistency in patient and control groups have been calculated separately and reported as  $\alpha = 0.82$  and  $0.80$  respectively (Docherty *et al.*, 2009). Within this study the ERS was also shown to predict psychotic symptom exacerbation over 9 months and furthermore to be associated with a differential effect of stressful life events on symptom increases.

***Brief Core Schema Scale (BCSS)***

***Fowler et al., 2006***

The Brief Core Schema Scales (BCSS) consist of 24 statements representing positive and negative evaluations of self (*e.g. ‘I am valuable’; ‘I am unloved’*) as well as positive and negative evaluations of others (*e.g. ‘Other people are accepting’; ‘Other people are devious’*). Each scale comprises 6 items and individuals are asked to indicate firstly whether or not they endorse the belief (Yes/No response format) and secondly if they do affirm the belief, then they are asked to rate the strength of their conviction (1 - Believe it slightly, 2- Believe it moderately, 3 - Believe it very much, 4 - Believe it totally). Item scores for each of the scales are summed: 0-4 points per item, total scale 0-24).

The BCSS was developed within the context of cognitive models of psychosis, in which dysfunctional schemas (be these negative or positive) about the self and others can influence appraisals of cognitive and affective disturbances, and in turn the content and manifestation of positive psychotic symptoms (Garety *et al.*, 2001). Within this model negative schema can be conceived of as a cognitive mechanism by which early childhood adversity and trauma (associated with increased risk for psychosis) can influence present appraisals and attributions. It was intended that the BCS Scales would specifically capture negative evaluations of self and others as opposed to more global constructs of self-esteem (Fowler *et al.*, 2006). Particular negative schemata have been associated with dissociable psychotic

symptoms (*Freeman et al., 2008*). In addition, individuals with chronic psychosis have evidenced more extreme negative evaluations of themselves and others than controls (non-clinical student sample) whilst maintaining comparable levels of self-esteem (as measured by the Rosenberg Self Esteem Schedule) and positive evaluations of self and others (*Fowler et al., 2006*).

The BCSS have been validated favourably within non-clinical and clinical samples; in addition to individuals at clinical high risk of psychosis (*Addington et al., 2009*). Alpha coefficients for internal consistency are reported as 0.78 and 0.86 for the positive and negative ‘self’ schema scales, and 0.88 for the positive and negative ‘other’ schema scales within a non-clinical group (*Fowler et al. 2006*). In a sample of schizophrenia patients the values were similarly high (0.79 and 0.84 for positive and negative ‘self’ schema; and 0.84 and 0.87 for positive and negative ‘other’ schema). In terms of concurrent validity, the self subscales showed moderate to strong association ( $r=0.64$  and  $0.65$ ,  $p<0.001$  respectively) with the Rosenberg Self Esteem Schedule. Correlations for the other subscales were weak (*Fowler et al., 2006*).

### **8.3 Statistical Design**

Distribution of scores on the subscales of the CRQ and additional measures were assessed using the Shapiro-Wilks test. Pearson’s  $r$  and Spearman’s  $\rho$  together with Pearson’s chi squared tests for categorical variables and Mann Whitney U test for mean rank differences were used to explore the relationships between service user characteristics (age, sex, ethnicity, duration of illness, number of admissions, BPRS ratings, emotional reactivity, arousal predisposition and positive and negative beliefs about other people) and perceived Expressed Emotion. In the first of two main sections to the analyses concurrent validity was examined using Spearman’s rank partial correlations, taking into account symptom scores, emotional reactivity, arousal predisposition and positive and negative schema about others. Ratings on the main CFI-dimensions (critical comments, emotional over-involvement and warmth) were analysed as ordinal variables. However, phi coefficients were examined to

assess correspondence between perceived criticism and overall EE classification as binary variables. In a second exploratory section, principle components analysis was used to examine the structure and inter-relation of items in the scale. Oblique factor rotation was selected to enable correlation between components, as the main indices of EE are not mutually exclusive. Internal consistencies for the Emotional Over-involvement and warmth subscales of the CRQ were evaluated using Cronbach's  $\alpha$ . In addition, test-retest reliabilities for each subscale were obtained over time period median = 30, s.d = 10.2 for 15 individuals. All analyses were conducted using SPSS 18 (SPSS Inc. Released 2009. PASW Statistics for Windows, Version 18.0. Chicago: SPSS Inc.).

A sample size of N=40 dyads was determined a priori to ensure 80% power to detect correlations with  $r=0.42$  with a 0.05, 2-sided significance level, which are smaller correlations than those reported in a similar US study that examined associations between EE and perceived EE in White, Hispanic and African American carer-patient groups (Weisman *et al.*, 2006). This sample size was also selected based on evidence suggesting that the ratio of participants to items is as important an indicator in determining the stability of factor analyses as total sample size (Osborne & Costello, 2004). Although recommendations vary, the present pilot analyses were based on studies supporting the use of a ratio no lower than 5:1 (Garson 2008; Arrindell & van der Ende, 1985). The CRQ contains 8 items.

#### **8.4 Participants**

##### ***Service-user characteristics***

Forty-seven individuals receiving outpatient treatment from Early Intervention in psychosis services in London participated in the study having given their consent. In three instances accompanying carer interviews could not be completed. However, service user details were retained for the study for inclusion within a components analysis of the CRQ. The total sample was thus N=44 dyads for most analyses. Ninety-one percent had a (most) recent ICD-10 diagnosis of first-episode psychosis (F10-F29 & F30-33). Individuals were excluded

from participating if they had a primary diagnosis of alcohol or substance use dependency, organic syndrome or a learning disability. An adequate command of the English language was required to take part in the study as well as the ability to identify a main ‘carer’ with whom they have regular contact. All patients were receiving antipsychotic medication at time of assessment. Symptom scores were assessed using the Brief Psychiatric Ratings Scale. Service-user demographics are shown in **Table 22**.

**Table 22: Measuring Perceived Expressed Emotion: service-user characteristics, (N=47), recruited from early episode services**

No. of participants	47
Diagnosis	75% primary diagnosis: F20 – F29
Sex	66% Male
Age (mean years)	24.8 ± 4.9
Ethnicity	57% White British, 32% Black or Black British, 11% Mixed
Employment status	25% in PT/FT paid employment; 45% unemployed and not in education or volunteering
Living status	81% living with primary carer
Face-to-face contact	mean = 17.3 ± 11.2
Illness time (weeks)	median = 75, min = 12, max = 565
Number of admissions	median = 1, min = 0, max = 4
BPRS total score	mean = 32 ± 7

### ***Carer characteristics***

The main indicator variable used to assess the status of the caregiving relationship was amount of face-to-face contact per week with the service user. Both parties had to recognise the nominated person as fulfilling a principal caregiving role. However, additionally this person had to be in contact with them for at least 10 hours per week (with at least one face-to-face interaction). All carers taking part in the study were in contact with their service

users prior to and during their first signs and symptoms of illness. To be included in the study carers were required to have been fulfilling this role for at least 3 months. The carers were a mixed-ethnicity sub-sample of individuals who agreed to take part in Study 2, whose (service user) relatives also consented to the study. The mean number of weeks between carer and service user interviews was  $2.9 \pm 3.1$ . Carers with a primary diagnosis of alcohol or substance use dependency, organic syndrome, learning difficulties or without sufficient English to take part were also excluded from the study. Carer characteristics are given in

**Table 23:**

**Table 23: Measuring Perceived Expressed Emotion: carer characteristics, (N=44), recruited from early episode services**

No. of carers	44
Sex	83% Female
Age (mean years)	$51.3 \pm 9.7$
Ethnicity	61% White British, 35% Black or Black British, 5% Mixed
Employment status	61% in PT/FT paid employment; 25% unemployed/sick leave/incapacity benefits
Relationship to patient	85% parents; 9% partners; 6% family other

## 8.5 Results

Younger participants were marginally ( $p=.10$ ) more likely to perceive higher amounts criticism from their carers. There were no further relationships observed between gender, ethnicity, illness length or number of admissions and perceived expressed emotion. However, as predicted, measures of service-user functioning were significantly related to their perceptions of Expressed Emotion and were controlled for in partial correlation analyses of convergent validity (**Table 24**, emotional reactivity (ERS), arousal

predisposition (APS), negative and positive beliefs about others (BCSS\_neg, BCSS\_pos) and symptom scores on the BPRS).

**Table 24: Service user functioning and perceived Expressed Emotion, (N=47)**

Pearson's r	CRQ_CRIT	CRQ_EOI	CRQ_WA
ERS	.370*	-	-.336*
APS	.404*	-	-
BCSS_POS	.-	-.296*	-
Spearman's rho			
BCSS_NEG	.367*	.313*	-
Total BPRS	.395**	.403**	-

\* significant at  $p < .05$

\*\* significant at  $p < .01$

***Concurrent validity: the Camberwell Family Interview (CFI) and the CRQ***

Thirty-four percent of the carer sample (15/44) were rated as high EE using the CFI, with 40% (6/15) of these ratings made on the basis of critical comments ( $\geq 6$ ) and Emotional Overinvolvement ( $\geq 3$ ), a further 40% (6/15) as a result of high EOI alone (6/14), and the remaining fifth (3/15) on the basis of criticism alone. Two thirds of those scoring above threshold on the criticism scale were also rated as hostile (6/9). Additionally, sixty-six percent of the sample was rated as high in warmth (29/44).

Ranked scores on the CRQ perceived criticism question correlated positively with ranked ratings derived from the Camberwell Family Interview (CRQ\_crit;  $r_s = .367$ ,  $p = .02$ ). In adjusted analyses, this relationship was unaltered by the inclusion of ranked scores on measures of service user functioning (**Table 25, overleaf**). By contrast, the Emotional Overinvolvement (CRQ\_eoi) and warmth dimensions (CRQ\_warm) showed small and insignificant correlations with the CFI, although they were in the expected direction. This may in part be explained by a significant inter-scale correlation reported between CRQ\_eoi and CRQ\_warm ( $r_s = .354$ ,  $p < .05$ ).



**Table 25: Spearman's rank partial correlations CRQ and CFI scales, (N=44 dyads)**

N = 44	Median	S.D	Range	CRQ_crit	CRQ_eoi	CRQ_warm
<b>CFI_CRIT</b>	2.0	4.1	0-19	<b>.367*</b>	.042	-.202
<b>CFI_EOI</b>	1.0	1.6	0-5	.042	.056	-.143
<b>CFI_WARM</b>	3.0	1.4	0-5	-.247	-.100	.082
<b>CRQ_crit</b>	5.0	2.8	1-10	-	.263	-.089
<b>CRQ_eoi</b>	23.0	6.6	6-30	-	-	<b>.354*</b>
<b>CRQ_warm</b>	33.0	6.9	9-40	-	-	-

\* significant at  $p < .05$ \*\* significant at  $p < .01$ 

Conversion of scores on the perceived criticism question into a binary variable based on a cut-off rate above the median ( $\geq 6$ ) resulted in a significant correlation between individuals rated as high EE based on perceived criticism and those rated as high EE based on the CFI ( $\phi = .403$ ,  $p < 0.01$ ).

***Concurrent validity: the Camberwell Family Interview (CFI) and the CRQ, comparison across ethnicities***

A comparison was made in the correlations observed between scores on the CRQ scales and CFI ratings based on the self-identified ethnicity of service users. Participants of mixed heritage were excluded from the analysis ( $n=5$ ). Comparisons were made between those identifying as white British (WB,  $N=27$ ) and those identifying as black African, Caribbean or black British (BA\_BAC,  $N=12$ ). Although underpowered, the association between perceived criticism and CFI critical comments was concordant across the ethnic groups. This finding supports the reliability and cultural validity of the CFI ratings made in the present study (**Table 26, overleaf**). Notably, the CRQ items intended to assess Emotional Overinvolvement (which addressed worry and protective behaviours in carers) showed a markedly more consistent pattern of convergence with CFI ratings of EOI in BA\_BAC service users than WB. Moreover, perceived warmth in WB service users was associated

with less critical comments and Emotional Overinvolvement reported by carers in the CFI, but not particularly with greater warmth. By contrast, for BA\_BAC service users, perceived criticism was significantly and strongly associated with a lack of warmth as rated by the CFI, with the CRQ\_warmth scale showing non-significant trends in expected directions.

**Table 26: Spearman's correlations between CRQ and CFI scales by service user ethnicity, unadjusted, (N=39)**

		CFI_CRIT	CFI_EOI	CFI_WARM
WB, N=27	CRQ_crit	.279, p=.16	.113	-.189
	CRQ_eoi	.017	-.094	-.116
	CRQ_warm	-.314, p=.13	-.353, p=.07	.111
BA_BAC, N=12	CRQ_crit	.370, p=.24	.054	-.593*
	CRQ_eoi	.474, p=.12	.547, p=.06	-.321
	CRQ_warm	-.144	.387	.200

\* significant at p<.05

***Concurrent validity: the Experience of Caregiving Inventory, Family Attitude Scale and the CRQ***

Comparisons with carer self-report outcomes showed that perceived criticism was consistently correlated with the negative subscales of the Experiences of Caregiving Inventory (ECI) and with the Family Attitude Scale (Table 27, overleaf). Specifically for the ECI, it was related to the subscales measuring carer appraisals of loss (ECI\_loss), for example time spent thinking 'about his/her lost opportunities' or 'whether I have done something to make him/her have these problems', as well as difficult behaviours: him/her being 'moody', 'unpredictable' or 'irritable', and negative symptoms, for example him/her being 'uncommunicative' or 'not interested.'. For the CRQ\_eoi items, a significant correlation was reported with the positive subscale of the ECI measuring the good elements

of the relationship for carers, again suggesting that the EOI items included in the CRQ may have some cross-over with warmth. The direction of associations for CRQ warmth scale were however all as expected, and a significant association was also obtained with the subscale of the ECI assessing good elements of the relationship e.g that '*s/he has shown strengths in coping with their illness*' or '*makes a valuable contribution to the household*'.

**Table 27: Spearman's rank partial correlations CRQ and carer outcomes, (N=44)**

N = 44	Mean	Median	S.D	Range	CRQ_crit	CRQ_eoi	CRQ_warm
<b>ECI_DEPEND<sup>1</sup></b>	9.3	-	4.2	0-19	.256	.171	.010
<b>ECI_LOSS</b>	10.3	-	5.5	1-22	<b>.421**</b>	.094	-.224
<b>ECI_DIFFBEH</b>	10.4	-	7.2	0-31	<b>.340*</b>	-.145	-.280
<b>ECI_BACKUP</b>	10.2	-	5.4	1-20	.138	.107	.068
<b>ECI_FAMILY</b>	-	9.0	6.0	0-27	.262	.085	-.113
<b>ECI_SERVICE</b>	-	7.5	6.5	0-25	.072	.004	-.063
<b>ECI_STIGMA</b>	6.9	-	4.9	0-17	.216	.278	-.005
<b>ECI_NEGSYM</b>	17.5	-	10.8	0-46	<b>.384*</b>	-.076	-.230
<b>ECI_GOOD</b>	14.0	-	4.2	5-24	-.147	<b>.389*</b>	<b>.441**</b>
<b>ECI_POSITIVE</b>	15.6	-	6.0	2-31	.075	.160	<b>.260, p=.10</b>
<b>FAS_TOT</b>	31.1	-	18.5	0-77	<b>.435**</b>	-.099	-.133

<sup>1</sup> see page 9 for abbreviations

\* significant at p<.05

\*\* significant at p<.01

In verification of the pathway via which carer appraisals of the relationship might affect individuals, the number of critical comments made during the CFI interview was shown to correlate more strongly than the CRQ with scores on the ECI subscales of loss ( $r_s=.545$ ,  $p <.001$ ); difficult behaviours ( $r_s=.702$ ,  $p <.001$ ) and negative symptoms ( $r_s=.668$ ,  $p <.001$ ) as well as with total scores on the FAS ( $r_s=.712$ ,  $p <.001$ ).

***Internal consistencies and reliability***

Cronbach's alpha for the CRQ\_EOI scale (3 items) was calculated as  $\alpha = .830$ . Removal of the item '*how upset has X got if you were having trouble*' increased the association to  $\alpha = .884$ . For the four items in the warmth scale  $\alpha = .879$  and removal of the item '*how much does X like to spend time and do things with you*' increased the coefficient to  $\alpha = .930$ . In terms of test re-test reliabilities for  $n=15$  over the period median = 30.5 weeks,  $s,d = 10.2$ , correlations for the perceived criticism question were  $r = .604$ ,  $p < .05$ ; for the CRQ\_EOI items,  $r = .588$ ,  $p < .05$ . The warmth items did not correlate in test-retest reliability analyses ( $n=6$ ).

***Principal components analysis***

Extraction of three components at eigenvalues  $> .8$  accounted for 79.6% of the variance in the data. With the first component accounting for 41.9%, the second component accounting for 26.5 % and the third 11.3% of the variance. Item loadings  $> .5$  are listed in **Table 28, overleaf**. Whilst the component loadings were as expected from scale aggregation, the CRQ\_EOI item '*how upset has the individual got if you were having trouble?*' was significantly associated with both the EOI and criticism components. As expected the items that loaded on the warmth scale showed small negative correlations with the extracted perceived criticism scale. The joint loading of warmth and EOI items, and in particular perceived protectiveness, is consistent with the significant correlation obtained between ranked sum scores on the two scales shown in **Table 25, p. 200**.

**Table 28: Principal components analysis (oblimin rotation) for the 8-item CRQ**

N = 47	Perceived warmth	Perceived EOI	Perceived criticism
CRQ_PROTECT <sup>1</sup>	.345	<b>.929</b>	.110
CRQ_WORRIED	.183	<b>.884</b>	.247
CRQ_LOVED	<b>.941</b>	.345	-.307
CRQ_SPENDTIME	<b>.551</b>	.462	-.575
CRQ_UPSET	-.039	<b>.520</b>	<b>.713</b>
CRQ_CRIT	-.194	.156	<b>.840</b>
CRQ_CARE	<b>.942</b>	.252	-.197
CRQ_WARM	<b>.917</b>	.259	-.273

<sup>1</sup>See Appendix 6 for CRQ items

## 8.6 Discussion

### *Convergent validity*

Correlations between scores on the perceived expressed emotion items and responses given in the CFI were consistent with previous research. The single perceived criticism question correlated modestly with objectively-rated critical comments, even when controlling for the potentially confounding influence of symptomatology, including depressive symptoms, emotional reactivity and negative beliefs about the self and others. This replicates previous research (*Onwumere et al., 2009; Scazufca et al., 2001*), and further substantiates the assumption that responses given in the CFI ‘translate’ into interactions between carers and service users ‘at home’. Furthermore, it suggests that whilst individuals with psychosis may be vulnerable to distortions in perception as a result of illness, social cognition is not entirely compromised. This assumption is also supported by recent functional neuroimaging studies that demonstrate diminished or altered activation in relevant brain areas, but similar patterns of activity in response to facial emotion processing tasks, in individuals with schizophrenia by comparison to controls (*Li et al., 2010*).

A partly unexpected finding was that items included in the scale that were intended to measure perceived EOI did not correlate with EOI ratings made on the basis of the CFI. This confirms Cutting et al.’s results (2006). However, when correlations were observed across

the (albeit smaller) ethnic groups, the CRQ\_EOI scale seemed to perform better as a measure of EOI in BA\_BAC service users than WB service users. This would suggest that the items are not altogether unrepresentative of the attitudes and behaviours that evidence EOI. However, a correlation observed in the present study between the EOI and warmth scales suggests that items such as '*how protective do you think your relative has been of you*' may be perceived more positively by some patients than the intrusive behaviours that constitute 'overprotection' in CFI ratings. Medina-Pradas et al. (2011) have attempted to address this issue, and have reported positive correlations with EOI rated in the CFI, with the inclusion of questions such as to what extent do you '*feel controlled by*' your relative or to what extent do they make you feel like you are '*not capable of taking care*' of yourself.

Interestingly, patient perceived criticism in this study correlated with dimensions of carer burden. This is consistent with bivariate correlations in other studies (Möller-Leimkühler & Obermeier, 2008). In multivariate analyses, the relationship between these variables would not be expected to be as strong as the relationship between carer burden and CFI ratings - both measurements of carers' responses (Onwumere et al., 2009; Möller-Leimkühler & Obermeier, 2008). This was evidenced in the present study in that critical comments made during the CFI were found to correlate more strongly with dimensions of carer burden than CRQ scores. The relationships observed between carer burden and Expressed Emotion support previous research that suggests feelings of loss and longing (for the person their relative once was and their opportunities for the future), together with difficulties in understanding and dealing with problematic behaviours, may contribute significantly to carer distress, particularly in the early stages of illness (Patterson et al., 2005; Tennakoon et al., 2000; Tucker, 1998). Recommendations for how to help families deal with this common experience of grief and loss are integrated into practical guidance manuals for clinicians working with individuals with schizophrenia and their families (Kuipers et al., 2002).

Consistent with the findings of Medina-Pradas et al. (2011) the CRQ\_warmth items did not show convergent validity with the CFI. However, in this study there was a significant relationship between scores on the CRQ\_warmth scale and the subscale of the ECI that measures carers' positive appraisals of caregiving. This provides some further evidence for the potential concurrent validity of the scale. Correlations between perceived warmth and CFI ratings might be improved by the inclusion of items that are more clearly rooted in behavioural interactions between carers and service users rather than subjective feelings of 'being loved.' For example, *'how affectionate is your relative with you?'* or *'how sympathetic is your relative when you are having difficulties?'*

#### ***Inter-item correlations***

A principal components analysis of the items revealed a three-factor structure with items co-varying in linear combinations as expected. Extracting components at eigenvalues greater than .8 showed a cross loading for the item *'how 'upset' does your relative get if you are having difficulties'*, which contributed significantly to the algorithms representing the EOI and criticism scales. This suggests the need for a greater specificity in the wording of the question to differentiate between exaggerated displays of emotion, which are rated as evidence of Emotional Overinvolvement, and critical arguments. Medina-Pradas and colleagues (2011) for example tested the item to what extent your relative *'cries easily'* when you talk about your *'things'*. The cross-loading also potentially explains why the inclusion of a third component contributed less to explaining the variance in scores than the original single item variable. The single item criticism measure prevented extraction of a higher order factor at eigenvalues greater than 1.0. However, it correlated .586 with the EOI items in a two factor solution. This suggests that the items for EOI and warmth are at least capturing something basic about the opposing valence of the experiences in question.

The Brief Dyadic Scale of Expressed Emotion (Medina-Pradas et al., 2011) included four items assessing criticism which, together with an orthogonal rotation method, facilitated theoretical factor differentiation. However, research as yet does not suggest that increasing

the number of items measuring perceived criticism improves the ability of the scale to predict psychopathological outcomes (Renshaw, 2008). Kwon and colleagues (2006) analysed the relationships between scores on the single item perceived criticism measure, versus aggregate scores on an expanded 5-item scale, and relapse over 12 months in a small sample of females with depression. Although both measures correlated equivalently with outcomes independently, in multivariate regression, analysing both variables simultaneously, the single item was the stronger predictor of relapse. Moreover, the criticism items in the BDSEE (Medina-Pradas *et al.*, 2011) are very similar in content to one another. The rationale for the inclusion of more criticism items needs further evidence. A more useful aspect of the scale to develop might be the inclusion of items that differentiate between hostile and non-hostile forms of perceived criticism; criticism directed at an individual's character as opposed to an aspect of their behaviour (Peterson & Smith, 2010; Renshaw *et al.*, 2010). However, the current predictive validity of the single item, which appears easy to understand in psychosis and depression populations, might then be compromised

Eighty-four percent of the variation in the warmth items was explainable by a common linear equation, with the items '*to what extent do you feel loved by your relative*' and '*how caring of you are they*' correlating most strongly. By contrast to Medina-Pradas and colleagues (2011) orthogonally rotated components analysis, the results of the present study suggest a cross-loading with the EOI scale for the item '*the extent to which your relative likes to spend time and do things with you.*', although this was not significant, but it suggests this item is not needed.

### ***Reliabilities***

Modest test-retest reliabilities were observed for the perceived criticism and perceived Emotional Overinvolvement scales over a median period of approximately 6 months. This supports the underlying assumption that there is a degree of robustness to the measurement of perceived expressed emotion; that service users mental state did not result in the



production of random or distorted responses. The reliability of the warmth scale could not be confirmed due to the delayed addition of the items.

#### ***Limitations - the scale***

At study outset there was no single scale available in the literature that assessed the various dimensions of EE from a patient perspective. As a first step in remedying this, the study aimed to aggregate and analyse items obtainable from existing literature. However, the resultant scale was limited in that it comprised items measuring emotional overinvolvement that provisional evidence (*Cutting et al., 2006*) suggested may not be nuanced enough to capture the complexities of the intrusive, self-sacrificing and overprotective interactions measured by the EOI dimension of the CFI. In addition, the warmth items had shown a positive but insignificant correlation with CFI warmth in a previous assessment of convergent validity (*Medina-Pradas et al., 2011*). Although the scale performed better in the BA\_BAC sample in this study, overall the results replicate a lack of significant correspondence with the CFI.

Future scale development might therefore focus on new item generation and greater specificity in item wording. For example, the EOI items used in the scale were extended by Medina-Pradas et al. (2011) after the study commenced and in line with recommendations by Cutting et al. (2006), to assess directly service user's opinions rather than phrasing the questions in such a way that they require inference by the service user to determine the emotional states of carers. The reliability and convergent validity of any scale with the CFI might also be improved by ensuring the questions are grounded in observable interactions. In addition, more accurate measures might be obtained by asking service users themselves to describe how they experience a relationship which is characterised by emotionally over-involved behaviour, rather than depending on researcher-led item generation. Finally, the scoring of all items was standardised to a 0-10 ratings scale as a result of the sensitivity of principal components analysis to scale. However, it has been suggested that this may lead to response bias for individuals who find it difficult to provide ratings about a family member

on a scale (*Okasha et al., 1994*). Further trials could be conducted using a Likert response format (*as in Scazufca et al., 2001*).

#### ***Limitations - statistical analyses***

The findings do not contribute to the debate regarding the predictive validity of perceived expressed emotion, as it was designed as a cross sectional validation study. In addition, the results pertain to a relatively stable first-episode sample with mild to moderate levels of impairment and may not be generalisable to individuals with more chronic difficulties. Certainly, one of the limitations of principal components analysis (PCA) is that it assumes that the sample used is the population and therefore it restricts conclusions to the sample collected. Generalisability depends on the replication of the extracted component structure in other samples. However, in this case the analyses were exploratory and the purpose of the PCA was to examine the pattern matrix to contribute to the development of scaling of a small number of variables, rather than the reduction of many items. In fact the sample size was small according to some recommendations for PCA (*Garson, 2008*), although not all based on participant to item ratios (*Garson 2008; Arrindell & van der Ende, 1985*). It did not permit an appropriately-powered examination of the comparative validity of perceived criticism across ethnic groups, to test the suggestion that PC may be a better predictor of outcome in individuals from ethnic minority groups than CFI ratings (*e.g. Thompson et al., 1995*). However, the results of the comparison made were indicative.

Additional limitations associated with PCA include that it does not account for error variance in the item set. It assumes that for each item the proportion of common variance shared with other items is 1. Furthermore, it aims to explain the maximum amount of this total common variance using the smallest number of explanatory constructs, rather than assuming a certain number of latent factors. The information included may be better explained by a greater number of components. Emotional overinvolvement for example is a complex construct which could be disaggregated, despite the suggestion that the behavioural manifestations may be commonly rooted in concern and anxiety (*Vaughn & Leff, 1976*).

With this limitation in mind, the inclusion of components contributing less than one standard unit of variance (eigenvalue) in the resultant algorithms were examined in different pattern matrices. Indeed, when a threshold of 1.0 was used for extraction, the single PC item became aggregated with EOI in a two-factor structure. The current more complex solution (based on eigenvalues greater than .8) provided more information about which variables co-varied with more than one latent factor and may be redundant or ambiguous in wording in the scale. The use of an oblique factor rotation also allowed for correlation in latent components. However, aside from one cross-loading item, there was quite a clear dissociation in item to scale correlations. Alternative methods by which to overcome some of these limitations in more comprehensive future analyses would include common factor analysis, which is based on a priori assumptions about underlying factors or latent variable structural equation modelling which also allows for testing of previously identified hypotheses about covariance in items and can be used to take into account measurement error.

### ***Clinical Applications***

Item development for any scale assessing the patient's perspective on personal interactions with caregivers must be guided by its intended application or use. Hooley and Parker (2006, p.386) note that '*developing alternative measures of EE as opposed to 'better predictors of relapse' may reflect a reification of the EE construct that is neither warranted nor appropriate.*' The scale in the present study is not intended as an alternative measure of EE, but rather as a '*complement to its application*', (Medina-Pradas et al., 2011). The distinction needs to be drawn between the present search for a reliable indicator of the quality of caregiving relationships (which might be used to track therapeutic change) versus a search for alternative predictors of illness outcomes.

The CFI was developed to measure family interactions in psychosis, at a time when individuals were considered to have more diminished capacity to handle interpersonal interactions because of a purely biological condition. The early development of Family Interventions in psychosis was partially motivated by the idea that helping carers to cope

better and modify their behavioural interactions was a more accessible route to protecting patients who were vulnerable to environmental stress. However, it is now more commonly suggested that psychosocial interventions should involve collaboration with patients directly, aiming to reduce the levels of distress they experience from negative evaluation from significant others.

Miklowitz and colleagues (2005) suggest, for example, interventions targeted at developing emotional self-regulation skills to deal with interpersonal conflict; distress tolerance or cognitive restructuring for those with psychosis. Researchers elsewhere have looked at cognitive interventions aimed at ‘inoculating’ individuals to criticism, and there is some evidence that this can be helpful (*Finnegan, 2011*). Similar interventions might be envisaged that incorporate ‘boundary setting’ for perceived emotional overinvolvement, or re-channelling (reframing) carer concern into more positive interactions, when there is perceived lack of warmth in caregiving relationships (*Kuipers et al., 2002*). This may be particularly relevant to BA\_BAC service users and their carers for whom, it seems, perceived warmth may play a more active role in protecting against relapse and indicating difficulties in carers. For WB service users in the present study, perceived warmth was associated with a lack of criticism and emotional-overinvolvement in carers, but not with warmth directly itself. By contrast, for BA\_BAC service users, perceived criticism correlated with CFI criticism but was much more strongly associated with a lack of warmth. These findings support the argument of Miklowitz and colleagues (2005) that the extent to which a patient is upset or distressed by changes in emotional interactions with caregivers is a stronger predictor of outcomes than ratings of the interaction itself.

Miklowitz et al. (2005) also proposed a potential usage for a brief measure of patient perceptions of family relationships, for community clinicians who were unable to conduct more lengthy family assessments. The present study supports this application by demonstrating that patient perceptions of EE in family relationships cannot be reduced to signs and symptoms of illness. A brief measure of perceived EE would be clinically useful

and might help suggest more direct ways to intervene with patients in negative family settings.

## **Overall discussion and conclusions**

Informal caregivers make a significant contribution to the care of people with longstanding disorders and this care is dependent on their own continuing health. National strategies intended to support carers are predicated on need, and the identification of factors that enable us to prioritise those in greatest need. The first study demonstrated the significant health consequences of caregiving, even at lower levels of reported care. This is relevant to approximately 5.8 million people in England and Wales who currently identify themselves as informal carers (*White, 2013*). For individuals providing higher amounts of care (more than 20 hours per week) their mean excess score in comparison to non-caregivers was three points on the CIS-R for common mental disorders. To put this in perspective, in a complementary study, no equivalent change in CIS-R score was recorded in response to the unpleasant experience of job loss in two thirds of participants, a change score of one was observed for most of the remainder (*McManus et al., 2012*). According to the 2011 Census, over 2 million people fall into this ‘higher intensity’ caregiving group. Results from the APMS 2007 would suggest that the proportion of these individuals meeting clinical thresholds for psychiatric symptoms may be twice that observed in non-caregivers.

While these considerations will apply across jurisdictions, recent developments in the UK are of interest. As previously mentioned, the government is embarking on a new public health strategy, ‘*No health without mental health*’, which centres on the devolution of public health governance to local communities. ‘*Carers at the heart of 21<sup>st</sup>-century families and communities*’ is the title of the current UK Carers Strategy (2008, updated 2010). The Department of Health has funded a ‘*Supporting Carers in GPs programme*’ and, in association with the Royal College of General Practitioners (RCGP), has conducted a pilot training programme (2010) for GPs on best practice in incorporating a carer’s policy (*Jones et al., 2010; PRTC & RCGP, 2011*). Carers UK continues to train volunteer Carer Ambassadors to act as liaison officers in directing this policy in practice (*Carers UK, retrieved 2013*). However, despite positive feedback on the pilot, it was noted by

participants that *'services for carers were unlikely to improve significantly without incentives and additional resource.'* (Jones *et al.*, 2010). GPs are already taking on increased duties in administering the Clinical Commissioning Groups proposed by the Health and Social Care Bill. In addition, evidence suggests that taking on a caring role does not necessarily translate into increased contact with primary care (Arksey & Hirst, 2005).

Within mental health services, a formalised system for carers assessment already exists, the Care Programme Approach, yet recent research has documented difficulties with its administration and poor uptake rates in England (Burns *et al.*, 2012). Previous national surveys have recorded that individuals caring for someone with mental as well as physical difficulties are at greater risk of experiencing psychological distress (Singleton *et al.*, 2002). This finding is supported by the results of study two, in which nearly a third of carers of individuals with psychosis met clinical cut-offs for depression using self-report instruments, and two-thirds reported significant problems with sleeping. This was despite the majority of carer-participants being below the age of sixty, in some form of employment or retired, and in receipt of an income above £150 per week. The development of tangible actions to engage carers overall and to reach those who are members of already marginalised communities therefore remains a priority (PRTC, 2010).

This work includes tackling documented disparities in the experiences of carers and service users from ethnic minorities in the UK by comparison to white British residents. The last Schizophrenia guideline update (2009) specifically reviewed ways in which to promote equality of care for ethnic minorities. The guideline was prefaced with a comment from Bhugra (2009) who noted that the inequality faced by individuals with schizophrenia, including difficulties in gaining effective, evidence-based psychological and pharmacological interventions, *'are even more difficult to overcome for people from ethnic minorities, who often gain access to help at a very late stage.'* Research now suggests that duration of untreated illness may in fact be more prolonged for white British patients (Ghali

*et al.*, 2013). However, the routes to care and experiences thereof for ethnic minorities remain considerably worse. Issues for African and Caribbean individuals in particular were brought to light by a highly-cited report from the Sainsbury Centre for Mental Health (SCMH, 2002). The two-year mixed methods research study entitled '*Breaking the Circles of Fear*' detailed specific concerns about poorer quality of care for black African and Caribbean men. Following this the government launched its action plan to increase cultural competence/capability in the NHS and its five-year programme for *Delivering Race Equality* in mental healthcare, which closed in 2010 (DoH, 2003, 2005).

Despite these policy and service investments there is little concrete evidence of improvement in service outcomes (*Mental Health Network, MHN, 2012*). The *Count me in census* of all (32,799) inpatients in the UK reported that rates of admission remained higher than average in black African, black Caribbean and 'Other black' ethnic groups by comparison to 2005 statistics (*Care Quality Commission, CQC, 2011*). Referrals from the criminal justice system also remained higher than average for black Caribbean and African individuals (*see also Ghali et al.*, 2013), as did rates of compulsory admission and detention under the Mental Health Act (*see also Singh et al.*, 2007), as well as rates for the number of individuals held in seclusion in inpatient facilities (*Count me in, CQC, 2011*). There is additional evidence to suggest that these disparities are not unique to black males. Adjusting for social and clinical characteristics, black women in four London boroughs were also more likely to be compulsorily admitted than white British women (*Lawlor et al.*, 2010).

The large number of potential underlying reasons for these disparities suggests that there is no single determinant and therefore no single service-level solution. Continuation of ethnic monitoring (*Psoinos et al.*, 2011) and analysis of service provision by ethnicity (*Ghali et al.*, 2012), as well as ongoing evaluation of the efficacy of cultural competency training (*Bhui et al.*, 2013, *Bennet et al.*, 2011; *Bhui et al.*, 2007) contributes partially to addressing concerns about insitutional racism in psychiatric services (*Bhui et al.*, 2012). Further research in several areas can also inform understanding of, and approaches to, minority ethnic issues in



Early Intervention services. Firstly, a number of interesting recent studies have focused on the role of 'outsider status' and perceived discrimination and their contributions to psychosis risk, symptomatology and interactions with services (*Velting, 2013*). For example, Chakraborty and colleagues (2011) found a relationship between perceived racism and poorer treatment adherence and longer admission length in a sample of 100 African and Caribbean individuals with psychosis in the UK. Ideally, this evidence could inform staff training and education. Secondly, investigations into ethnic differences in help-seeking have revealed how different models of mental illness and attitudes to mental health issues may guide treatment decisions (*Lawlor et al., 2012, Archie et al., 2010, Singh & Grange, 2006*). These studies are informative for anti-stigma and community outreach and education programmes (*Knifton et al., 2012*). Thirdly, emerging research into the links between psychosis and trauma (*Berry et al., 2013*) could be developed considerably in relation to the experiences of immigrants and ethnic minorities. For example, a recent study observed a correlation between earlier age at migration and increased risk of psychosis (*Velting et al., 2011*). In addition, negative experiences of treatment, recurrent episodes of psychosis and longer periods of hospitalisation have been associated with higher levels of PTSD symptoms in individuals with psychosis (*Berry et al., 2013*).

Perhaps surprisingly, despite these disparities, empirical studies of patient experience have not reported blanket dissatisfaction amongst black service users (*Raleigh et al., 2007*). Well-controlled studies exist that have shown (within particular regional areas) that there may be little ethnic variation across many domains of service user satisfaction (*Boydell et al., 2012*). However, this same study reported that black Caribbean patients were less likely than white British patients to believe that they were receiving the right treatment and were less satisfied with medication. Black African patients were also less satisfied than white British patients with non-pharmacological treatments. These findings present an opportunity for the development of clinical services in psychosis for ethnically diverse patients. Overall, it is estimated that only one in ten individuals with psychosis in the UK has received cognitive

behavioural treatment for illness in addition to pharmaceutical interventions (The Abandoned Illness, Schizophrenia Commission Report, 2012). This is despite service-user demand and an evidence base to support its efficacy (NICE, 2009). Some researchers have recorded higher drop-out rates and poorer response amongst African Caribbean and black African patients by comparison to white British patients in a trial of a CBT intervention targeting insight in psychosis (*Rathod et al., 2005*). However, this is not true of all trials of CBT interventions in psychosis (*Peters et al 2010*). Provisional qualitative work has examined how training manuals for CBT in psychosis might need to be adapted in order to improve experiences for ethnic minorities (*Rathod et al., 2010*). However, details on how these differences might translate into technical adaptations are yet to be published and randomised controlled trials of culturally adapted CBT for psychosis have yet to include comparisons to standardised CBT for psychosis (*Rathod et al., 2013*).

Within this context, the corollary experiences for black African and Caribbean relatives and carers of individuals with psychosis may also be particularly aversive. However, little is known about their perspectives (*SCMH, 2002*). In a review of the efficacy of Family Interventions in psychosis, as assessed in randomised controlled trials, the Schizophrenia guidelines update (2009) documented the utility and cost-effectiveness of FI in relation to patient outcomes. However, carer outcomes have received less attention (*Lobban et al., 2013*). Furthermore, the efficacy of interventions is yet to be examined for carers from white non-Western backgrounds (NICE, 2009). For example, in a recent large-scale (n=103) feasibility study of a supported self-management intervention for relatives of people with recent onset psychosis (the REACT study) the demographic of the locality resulted in a recruited sample that was 94% white British (*Lobban et al., 2013*). Given the results of study two herein, which documented ethnic differences in coping styles, attributions about the causes of illness and interactions with service users, future trials of carer interventions might usefully expand feasibility studies to more culturally diverse samples.

The question therefore continues to be debated as to how best to respond to the needs of ethnically diverse communities (Bhui & Sashidharan, 2003). There is agreement by and large that there is neither the resource, nor the evidence to support ethnic matching in psychological services (Ascoli *et al.*, 2012). Hence, recent advances have been made in developing guidelines for cultural formulations in clinical practice (Alarcón *et al.*, 2009). Cultural ‘consultancy’ services are being trialled in certain areas of London (Bhui *et al.*, 2012) and investigations are being conducted into how established interventions might need to be adapted in order to be acceptable to individuals from different ethnicities and to be effective for them (*e.g.* Bradley *et al.*, 2006). There are few studies that have examined what these modifications might ‘look like’ for FI in psychosis, particularly in the UK. Hence, the research recommendations made in the NICE schizophrenia guideline update (2009) included an assessment of ‘*whether ethnically adapted family intervention for schizophrenia (adapted in consultation with black and minority ethnic groups to better suit different cultural and ethnic needs) enable more people in black and minority ethnic groups to engage with this therapy, and show concomitant reductions in patient relapse rates and carer distress.*’

Addressing these concerns, the results of Study 2 suggested that illness beliefs, coping styles and the relationship between appraisals of caregiving and resultant distress may differ in systematic and interpretable ways across ethnic groups. The study hypotheses were partially supported in that higher warmth was documented in black African and Caribbean (BA\_BAC) carers in comparison to white British carers (WB), as well as higher endorsement of external illness causes and a weaker relationship between negative appraisals of caregiving, EE and distress. However, it is unclear whether these differences imply any changes to the content or structure of FI to make it more suitable for application with diverse ethnic groups. The observation of a reduced rate of high EE in BA\_BAC carers, despite equitable levels of distress, certainly underscores the importance of supporting Low EE families pre-emptively. The findings might also be considered within the context of

direct work with carers rather than FI for psychosis. Studies reporting on the impact of interventions on carer outcomes and well being, in addition to patients, are limited (*Lobban et al., 2013*).

The observation of higher rates of religious coping in BA\_BAC carers in Study 2 and its significant association with warmth in the caregiving relationship also re-raises the clinical issue of how to work with sensitivity to the role of religion in a person's life (*Smolak et al., 2012; Leavey et al., 2012; Borrás et al., 2010; Mohr et al., 2007*). One carer-participant suggested increasing awareness and sensitivity amongst staff delivering psychoeducation to different belief systems and how these can lead to conflict in understanding expressions of religious belief during periods of illness. The same participant noted her perceived role as mediator between her relative and medical services, interpreting communications from health services within a religious framework to facilitate service user engagement with treatment.

The finding of a higher rate of warmth in BA\_BAC carers, combined with the importance - of its absence - to patient's perceptions of criticism, requires confirmation. Further exploration would be helpful to ascertain whether modifiable cognitive and behavioural predictors of high warmth can be identified in carers of different ethnicities. The results of study three provide proof of principle evidence for the reliability, validity and utility of a measurement of the quality of the caregiving relationship for administration with service users that incorporates each of the indices of EE. A fully-developed measure might firstly offer a way to assess more immediately the impact of social interactions for service users and to evaluate the effects of therapeutic interventions over time. If the reliability of a measure could be re-confirmed within a psychosis sample this would also enable the time period to be shortened over which change could be observed clinically. Secondly, its development would enable comparisons to be made in how familial and caregiving interactions 'translate' within a sociocultural context, that is based specifically in the schema of the individual in question rather than measured via a proxy variable e.g self-ascribed

ethnicity. This might allow the debate to advance from searching for systemic ethnic or cultural differences in the expression of EE responses in carers towards the integration of individual differences in the interpretation of EE responses, which may be influenced by culture, into ethnic non-specific measurement instruments.

One of the central issues raised by the research was how best to approach the study of cultural differences. Although acculturation measures provide taxonomies by which to measure the potentially stress-inducing experiences of cultural conflict and exchange, they do not necessarily incorporate dimensions of immediate relevance to the outcome variables or mechanisms in question. Forthcoming attempts to refine Bhugra and MacKenzie's (2003) schematic of cultural characteristics influencing Expressed Emotion (**Figure 5, p. 101**) might investigate ethnic-specific commonalities in individual locus of control, belief-flexibility, stressful life events, social networks, the strength of the relationship between cognition and affect or the influence of religious belief. However, recruitment of a sizeable, homogenous sample that enables definitive statements to be made about the influence of cultural systems is a significant barrier to this kind of research, particularly in cities like London that have a long history of immigration. It has been argued that the conflation of culture and religion in research is also '*a barrier to isolating the common mechanisms across the world religions that impact schizophrenia.*' (Gearing et al., 2011, p.152). Borras and colleagues (2007) concur that the influence of religious belief is understudied in mental health research.

The studies in this thesis have in part attempted to address the issue of modifying FI in psychosis for use in multicultural communities by examining ethnic differences in cognitive processes of caregiving. This has focused on whether the cognitive mechanisms that underpin FI for psychosis might be different to individuals of different ethnicities; whether the theory requires alteration. Much of the research to ensure the efficacy and acceptability of psychological interventions for individuals from ethnically diverse backgrounds is funded by the government, and embedded in policy directives. With the Delivering Race Equality in

mental healthcare programme closing in 2010, concerns remain about advancing research and practice agendas without a co-ordinating support structure (MHN, 2010). It is important that amongst the research methodology, practical and financial challenges, we do not lose the voices of the individuals who are affected, as these illustrative quotes demonstrate.

**Mother, 50, white Irish, C149:** ‘I come from a very narrow minded Irish family and I’ve tried to hide it, but I can’t hide it any more. I don’t care what people say, there’s a lot of stigma attached to this and I am very angry about it.’

**Mother, 51, white British, C075:** ‘I think it’s, as a carer if you like, it still does feel like you’re isolated. I would have liked to have been in on the initial meetings with the psychiatrist. I felt very voiceless at the beginning.’

**Mother, 55, black African, C160:** ‘It took a while for me to accept it, more so because of my culture. You know culturally speaking we don’t even mention it. You know mental health is taboo, you don’t mention it or you think you are the only one suffering from it, so you want to hide it, but eventually it could happen to anybody at anytime. It’s not because maybe you are African or whatever, or because some spirit is after you. It’s just, since this, it just opened my understanding of the sickness, of the difficulties and the help that is there.’

**Mother, 60, black British, C147:** ‘With my son, I feel like he went to a place of hell and I went with him. It’s almost like a wall and I went over that wall with him and I held him over the other side of that wall and I pulled him back out and I got him back out through there. It took a long time and then I saw my daughter and I don’t think that I can do it again. I don’t think so. I don’t think I have the capacity. I don’t think I have the heart. I don’t think I have the spirit. It takes too much away from you. It’s too painful.’

**Mother, 47, white English, C190:** ‘There have been a couple of times actually where he has been violent towards me. He hurled a kitchen knife from one end of the hall to the other. He put my front door through which I got him arrested for and two years ago he had a big fight with his brother...even though...he wasn’t really provoked, no! That’s me trying to stand up for him now, I don’t know why.’

**Mother, 47, black African, C242:** ‘and he came and said mummy, can I say something, ‘oh I love you so much’ and it’s something he hasn’t said for a very long time, ‘I love you so much’, and I said that’s the best Christmas present I could ever have.’

**Mother, 60, black British, C147:** ‘There is this perception of young black men being aggressive and criminally ‘note’ and therefore their intervention would be different in terms of the resources, just in terms of we talk about talking therapy that’s never been offered to my son, and that’s throughout his mental health problems and the severe way that he would be perceived by members of staff and I think that there is this perception of being more out of control if you are a black individual and that’s where the discrimination comes into it.’

**Father, 57, black Caribbean, C241:** ‘Who do you talk to when you have concerns about a family member; you talk to the family don’t you? They didn’t and they haven’t (services).’

**Mother, 55, black African, C160:** ‘I think it’s because maybe people from my background when they know that people in your family have that type of tendency to have a mental breakdown they don’t want to ask to stay with you, they don’t want to get married to your family, and you become an outcast so to speak.’

***Mother, white British, C273:*** ‘I think if anything it’s probably actually brought us (family) closer together, really.’

***Mother, 55, black Caribbean, C256:*** ‘He’s not that bad that he can’t deal with society, you get me? And the more you keep them in society, those things the better for them.’

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**Appendix 1:**

**Table 2: Review of studies of EE across cultures**

Reference	Year	Study	Sample	Study Design	EE Measure	Conclusion
Roseliza-Murni et al.	2013	Schizophrenia relapse in Kuala Lumpur, Malaysia: Do relatives' expressed emotion and personality traits matter?	160 Malaysian patients and carers	Prospective, 6 month f/up, outcome = re-hospitalisation	Weideman's carer self-rated 20 item Family Questionnaire (FQ, 2002)	Support for cross cultural validity of EE  High EE = 8 x more likely to be readmitted
Singh et al.	2013	Cultural Specificity of Emotional Over-involvement: A Systematic Review	-	Systematic review of 34 studies of EOI across cultures. n= 28 investigating if EOI has same outcome, follow-up period and measurement instrument noted. n=X on culturally adapted norms.	Notes heterogeneity in methodologies across studies prevents a meta-analysis that could allow for quality adjustments.	The relationship between high EOI and outcome is inconsistent across cultures.  Attempts to improve predictive validity by post-hoc adjustments had varied success.  Measurement issue but also suggestion EOI is culture-specific. High EOI may be moderated by warmth and interdependence.
Lloyd et al.	2013	Sources of parental burden in a UK sample of first-generation North Indian Punjabi Sikhs and their white British counterparts.	23 British Indian Punjabi Sikhs 16 White British dyads	Cross-sectional comparison of rates of EE and correlates	Five Minute Speech Sample (Magana 1986)	56% high EE in British Sikhs. 19% high EE in White British No relationship reported between burden and EE in either group.
Michelson & Bhugra	2012	Family environment, expressed emotion and adolescent self-harm: a review of conceptual, empirical, cross-cultural and clinical perspectives	-	Narrative review of evidence on for the influence of family environment on self harm in adolescents	-	Emerging evidence for an association between high EE and adolescent self-harm requires replication in well-controlled, prospective studies  Positive aspects of family interaction tend to get ignored in most studies on EE.  Need to take into account interactions between critical and protective factors like warmth.

**Appendix 1:**

**Table 2: Review of studies of EE across cultures**

Hoste et al.	2012	Cultural variability in Expressed Emotion among families of adolescents with anorexia nervosa.	189 ED patients & family 76% White sample. Mixed Asian & Hispanic group.	Cross sectional comparison in proportions /mean differences in EE.	Kinston's Structured Clinical Family Interview (SCFI, 1984)	Few differences in EE, CC, H, EOI  White group had higher warmth.
Carrà et al.	2012b	The association between expressed emotion, illness severity and subjective burden of care in relatives of patients with schizophrenia. Findings from an Italian population	320 Italian patients, 205 carers, no ethnicity given	Cross-sectional exploration of prediction of EE by burden	Camberwell Family Interview (CFI)	Confirmed association between high EE and greater subjective burden. There is a need for cross-cultural comparisons of the subjective experience of distress and burden among high EE carers
Subandi	2011	Family expressed emotion in a Javanese cultural context.	9 Javanese first episode patients & carers	Ethnographic study. Monthly visits over 12 months	Also used LEE as global measure (not indices)	Co-existence of criticism and warmth, as noted in early studies by Wig 1987, an important feature.
Suhail et al.	2011	Ethnographic analysis of expressed emotions in pakistani families of patients with schizophrenia	64 families in Pakistan	Cross-sectional analysis of CFI content.	Uses content from CFI	Frequency of statements relating to EOI greater than either criticism or hostility. Criticism mostly directed at socially objectionable behaviours.
Aguilera et al.	2010	Expressed emotion and sociocultural moderation in the course of schizophrenia	60 Mexican-American caregivers and their ill relatives	Prospective, 12- month f/up. Examined EE and relapse (hospitalization/symptom exacerbation) & EE and symptomatology (BPRS) longitudinally. Also examined if bidimensional US acculturation/Mexican enculturation moderates these relationships (language as proxy).	CFI	43% high EE, 50% due to EOI, 18% CC. Adjusting for medication adherence. High EOI predicted relapse; CC and W did not. Suggest EOI most predictive index in Mexican Americans. High EE overall not predictive of increased symptomatology over 12 months but CC did. Increased EOI-relapse rates when Mexican enculturation (patients?) low. Higher EE association with less Mexican enculturation.
Chan	2010	Negative caregiving experience: A Predictor of High Expressed Emotion Among Caregivers of Relatives with Schizophrenia	61 carers, 51 relatives in China	Cross sectional hierarchical regression	FQ	Confirmation of burden-EE association. Difficult disruptive behaviours/lack of insight no longer significant in a predictive model of CC and EOI once subjective burden entered into regression model.

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**Table 2: Review of studies of EE across cultures**

Chentsova-Dutton et al.	2010	Further evidence for the cultural norm hypothesis: positive emotion in depressed and control European American and Asian American women.	-	-	-	Depression reduces ability to express culturally consistent emotions. Makes Euro-American less positively or negatively expressive (facial expressions, speech, cardiac response) and Asian American less able to moderate demonstrable emotional response.
Jadhav	2009	What is cultural validity and why is it ignored? The case of Expressed Emotions research in South Asia	-	Commentary article	-	Underscores need to develop indigenous concepts of emotions expressed in their full range.  Notes 'It is indeed surprising that there is not a single study examining the role of Expressed Emotions amongst the British Black population, despite concern over increased incidence.'
Lopez et al.	2009	Cultural variability in the Manifestation of Expressed Emotion	224 patient/carers 76% Mexican American (MA) 24% Anglo-American (AA)	Cross sectional comparison of rates of high EE and prevalence of indices of EE. US Acculturation measured 12 item Eng language use and media preferences.  Pooled data (MA: Lopez 2008, Dorian 2008, Kopelowicz 2006; AA: Vaughn 1984, Karno 1987)	CFI	AA had significantly higher rates of EE (67% vs 37%) higher criticism, less warmth and less EOI than Mexican Americans in adjusted analyses. Lower carer acculturation in MA associated with less criticism (p<.05).
Ewhrudjahpor et al.	2008	Case Studies of Family Expressed Emotion for Persons Living with Schizophrenia in Delta State of Nigeria	31 families in Nigeria	-	CFI	80% High EE based on 20 or more critical comments. Associated with shame and poverty. High EE associated with number of relapse but f/up time period unclear.
Hoste & le Grange.	2008	Expressed emotion among white and ethnic minority families of adolescents with bulimia nervosa	55 patients with ED and 84 parents 74% white, 6% black, 13% Hispanic, other.	Cross sectional comparison of rates and indices of EE.	Structured Clinical Family Interview	No significant differences in EE or indices.

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**Table 2: Review of studies of EE across cultures**

Kymaleinen & Weisman de Manami	2008	Expressed Emotion, Communication Deviance and schizophrenia – a review of the literature	-	Critical review	-	Notes 3 studies in which criticism in Black American families was not predictive of relapse. Moline (1985) at no threshold. Tompson (1985) patient perceptions a better predictor than objective EE ratings in African Americans. Rosenfarb 2006: no association between high EE and burden in black families.
Koneru & Weisman de Manami	2007	<b>Acculturation and Expressed Emotion</b> in Caucasian, Latino, and Black Relatives of Patients with Schizophrenia	20 Caucasian, 21 Latino 16 black caregivers of schizophrenia patients	Cross sectional examination of the association between Acculturation and EE.	CFI Adapted version of the Suinn Lew Acculturation scale (to US culture) What are Caucasian acculturating to?	Greater acculturation associated with high EE in Latinos and low EE for Blacks and Caucasians.  Greater acculturation significantly and positively correlated with criticism in the combined group. On subgroup analyses this stood for Latinos but not black or Caucasian carers.
Breitborde et al.	2007	Toward specifying the nature of the relationship between Expressed Emotion and schizophrenic relapse.	44 Mexican American dyads, reanalysis of Karno 1987	Prospective, 9 month follow up.	CFI	Application of a quadratic rather than linear regression in EOI was a better predictor of relapse. Relationship best modeled by a J shaped curve.  EOI and warmth were predictive of relapse in this sample but not criticism. High warm may 'buffer' against effect of high EOI.
Weisman de Manami et al.	2007	<b>Expressed emotion</b> and interdependence in <b>White and Latino/Hispanic family</b> members of patients with schizophrenia	21 Latino 20 White carers	Cross-sectional examination of the associations between EE, interdependence and ethnicity.	CFI and FMSS	Whites designated as high EE significantly more often than Latinos/Hispanics (47% vs 15%). Strong trend for Latino/Hispanics to report a more interdependent self-construal than did Whites. But interdependence not found to mediate the relationship between ethnicity and EE.

**Appendix 1:**

**Table 2: Review of studies of EE across cultures**

Healey et al.	2006	Cross-cultural validation of expressed emotion in caregivers of Chinese patients with first episode psychosis in Singapore: a qualitative study.	10 Singaporean patient-carer pairs	Qualitative interviews analyses for evidence substantiating Vaughn and Leff's (1985) qualitative descriptions of high and low EE characteristics.	LEE Scale	Validation of EE concept in China.
Kopelowicz et al.	2006	Expressed emotion and family interactions in Mexican Americans with schizophrenia	24 Mexican American dyads	Prospective follow-up, 12 months. Relationships between EE, structural family interactions and relapse examined.	CFI	33% High EE, mostly EOI. High EE associated with relapse.
Nomura et al.	2005	A cross-cultural study on expressed emotion in carers of people with dementia and schizophrenia: Japan and England	20 Japanese dementia carers 20 English dementia carers 20 J/20 E schizophrenia carers	Cross sectional comparison of association between EE and burden in England and Japan.	CFI	EE only correlated with burden in Japanese dementia with flexible cut off rates (>2 crit)  Large differences between Japan and England were found in the frequency of critical comments, in which ES>ED>JS>JD  Tendency for lower expression of both positive and negative emotional reactions towards family members in the Japanese sample.
Rosenfarb et al.	2006a	Family interactions and the course of Schizophrenia in Black and Caucasian patients	40 Black African Americans 31 White Caucasian American	Follow-up over 2 years, patients randomized to double blind medication conditions.	Family Problem-Solving Task (FPST; Bellack et al., 1996).	For African American patients, high levels of relatives' critical and intrusive behavior were associated with better outcome. For White patients, low levels of both relatives' critical and intrusive behavior and patients' odd or unusual thinking with relatives were associated with better outcome.
Weisman et al.	2006	Ethnicity, expressed emotion, and schizophrenia patients' perceptions of their family members' criticism.	42 relative/patient dyads; 15 non-Hisp. White, 13 Latino; 14 Black	Cross-sectional investigation of the association between PC and EE across ethnic groups.	CFI, PC	No association reported between EE and PC in Black group.

**Appendix 1:**

**Table 2: Review of studies of EE across cultures**

Lopez et al.	2004	Ethnicity, expressed emotion, attributions, and course of schizophrenia: family warmth matters	Re-examination of 54 Anglo American Vaughn 1984 and 44 Mexican American Karno 1987.	Cross sectional and prospective studies. Examination of attribution model in EOI and ethnici	CFI	<p>Criticism did not predict relapse in MA sample.</p> <p>Family warmth a significant protective factor for Mexican Americans</p> <p>2 empirical studies showing patients were less likely to relapse when they returned to households high in warmth than when they returned to households low in warmth (Bertrando et al., 1992; Ivanovic et al. 1994).</p> <p>‘Apparent paradox of significant ethnic differences in EE and conceptualizations of schizophrenia but no differences in relapse rates warrants further investigation.’</p>
Bhugra & McKenzie	2003	Expressed Emotion across cultures	-	Review of existing findings: (Wig 1987, Kamal 1985, Okasha, 1994, Heresco-Levy 1990, Phillips & Xiang 1995, Mino 1995, Jenkins	-	<p>If measures of EE are to be applied to other cultures, must be accompanied by fieldwork to establish norms of the context.</p> <p>Levels as well as prevalence of components of EE reported in non Westerns countries vary.</p> <p>Components of EE must be seen in cultural context and embedded in normative data.</p>
Reicher	2003	Emotional reactions of relatives to schizophrenic patients in Lagos, Nigeria.	19 Nigerian born individuals with schizophrenia	Cross sectional analysis of rates of EE, its indices and correlations	CFI	63% of families High EE in Nigeria. Mean CC = 6. EOI 26%, Hostility 32%



### Appendix 1:

**Table 2: Review of studies of EE across cultures**

Ran et al.	2003	The characteristics of Expressed Emotion among relatives of patients with schizophrenia in Chengdu, China	71 patients and key relatives	Cross sectional analysis of rates of EE and its indices. Reliability of translated CFI.	Mandarin version of the CFI	28% HighEE. Reported fewer EOI behaviours and critical comments than participants in similar Western studies. Urban/Rural comparison. City dwellers more expressive in their reactions.
Cheng	2002	Is Expressed Emotion a cross culturally valid concept?	-	Editorial	-	-
Kopelowicz et al.	2002	Evaluation of expressed emotion in schizophrenia: a comparison of Caucasians and Mexican-Americans	17 Caucasian 44 Mexican	Cross sectional and predictive (2 yr f/up) exploration of association between effects of social desirability (restricted reporting or expressing of issues) and EE to explain low levels of criticism and hostility reported in Mexican American samples. Comparison of patient and carer measures.	LEE FMSS	No differences between patient and family measures of EE within ethnic groups. MA had lower rates of High EE than Caucasians on all measures. High EE (crit) did not predict relapse in MAs but did for Caucasians.
Mottaghipour	2001	Expressed Emotion and the course of schizophrenia in Iran.	78 Iranian patients 97 family members	Prospective, follow-up over 9 months. Symptomatology (clinical interview) as outcome indicator.	CFI	60% High EE households No association between High EE and relapse. (but positive if no recovery included). Unclear how controlled for symptoms. No association with no. of admissions but symptomatology?
Hashemi & Cochrane	1999	Expressed emotion and schizophrenia – a review of studies across cultures	60 families, 20 British Sikhs, 20 British Pakistanis, 2- matched British Whites	Cross sectional comparison of proportions of High EE and distributions of indices.  Prospective study of relapse (no details). Reviews: Karno 1987 – MA, Wig 1987 - Indian, El Islam (1982) - Arabian, Kamal et al. 1995 – Egypt; Okasha (1994) Egypt. Philips & Xiong (1995) – China. Mino et al. (1995).	Unpublished	80% High EE BP, 45% White, 30% BS.Failed to demonstrate an association between high EE and relapse when considering British-Pakistani and British-Sikh groups. High EE (EOI) noted as norm amongst Pakistani Muslim families. The author argues that high EE within these ethnic groups may be reflective of a typical familial communication style as opposed to a pathogenic trait.

**Appendix 1:**

**Table 2: Review of studies of EE across cultures**

Lefley	1998	The Family Experience in Cultural Context: Implications for Further Research and Practice	-	Review article discussing influence of individualistic versus sociocentric cultures on perceived autonomy and independence (control and blame). Ethnic group differences in EE profiles. Social support networks.		Suggestion Low EE normative to 'traditional' cultures.
Weisman	1997	Understanding cross cultural prognostic variability for schizophrenia	-	Review article considering the role culture (via religiosity and family cohesion) may have on attributions of control and blame to patient, and therefore resultant emotions, particularly in a Hispanic context.	-	Exploration of utility of attributions model in understanding differences in EE rates across cultures, perceptions of control. Weisman 1993 attributions Role for religion and supernatural in influencing models of illness & kinship structures.
Tanaka et al.	1995	Expressed Emotion and the course of schizophrenia in Japan				
Tompson et al.	1995	Schizophrenia patient's perceptions and their relative's attitudes	33 outpatients and 36 significant others  30% White-Americans, 46% African-Americans 15 % Latino 9% Asian	Prospective 1 year f-up, comparison of EE versus perceived criticism in predicting symptom exacerbation.	FMSS	No relationship between EOI and psychotic exacerbation at 1 year follow-up in any group.  PC predicted outcome in African American groups 87% of the time.  When family environments are examined in patients of ethnic minority groups, the patient's perspective may be a more potent predictor of outcome than traditional measures of EE.  Suggestion that black families might experience critical and intrusive behavior as a symbol of engagement, caring, and support (Davidson, 2001)

**Appendix 1:**

**Table 2: Review of studies of EE across cultures**

Jenkins & Karno	1992	The Meaning of Expressed Emotion: Theoretical Issues Raised by Cross-Cultural Research. American Journal of Psychiatry	-	Critical review of literature for differences in EE rates and prevalence of indices across ethnic groups	-	Conceptualisation of EE as dictated by cultural transgressive behaviours. Criticism as “negative response to perceived cultural rule violation” p.403 over-involvement should be seen as “behavioral transgression of boundaries. p.411 Discusses influence of culture on <i>Cultural Interpretations of the nature of the problem, meanings of kin relations, identification of cultural rule violations, vocabularies of emotion, personality traits or dispositions, degrees &amp; kinds of psychopathology, family interactive dynamics, social control, quality and availability of social supports.</i>
Jenkins and Karno	1986	Expressed Emotion in Cross-Cultural Context: Familial Responses to Schizo. in MAs	-	-	-	31% High EE in Mexican Americans 61% High EE in Euro Americans
Moline et al.	1985	Family expressed emotion and relapse in schizophrenia in 24 urban American patients	24 patient/carer dyads 66% Black	Prospective correlation between EE and relapse. Relapse measured as significant increase in first rank symptoms.	CFI	First to investigate expressed emotion in a mixed Caucasian and black sample, predominantly inner-city, lower-socioeconomic-class population. black subgroup did not demonstrate a significant correlation between expressed emotion and relapse at any cut-off point

**Berkshire Research Ethics Committee**

Building L27  
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London Road  
Reading  
RG1 5AQ

27 October 2010

Telephone: 0118 918 0550 / 0551  
Facsimile: 0118 918 0559

Miss Lindsay Smith  
Post Graduate Researcher  
King's College London  
Institute of Psychiatry  
P048; Addiction Sciences Building  
4 Windsor Walk, London  
SE5 8AF

Dear Miss Smith

<b>Study Title:</b>	<b>The role of socio-cultural differences in care-giving processes in psychosis</b>
<b>REC reference number:</b>	<b>10/H0505/79</b>
<b>Protocol number:</b>	<b>N/A</b>

Thank you for your letter of 24 September 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Investigator CV		01 March 2010
Protocol	2	17 July 2010
CV: Prof E Kuipers	By email	01 August 2010
Project Approval Review Form - Reviewer's Report		24 November 2009
Zurich Insurance, Policy No. NHE-01CA25-003		29 July 2010
REC application	3	23 July 2010
Covering Letter		
Letter from Sponsor		22 March 2010
Letter of invitation to participant	4	04 September 2010
Participant Information Sheet: Carer: Study 2	5	04 September 2010
Participant Consent Form: Service User	5	04 September 2010
Response to Request for Further Information		24 September 2010
Participant Information Sheet: Carer: Study 3	5	04 September 2010
Participant Information Sheet: Service User: Study 2	5	04 September 2010
Participant Information Sheet: Service User: Study 3	5	04 September 2010
Participant Consent Form: Carer	5	04 September 2010
Reviewer's Comments		27 November 2009
Letter from King's College London re: Insurance		05 July 2010
AON Insurance	To 2012	01 September 2009
Letter of Reply to reviewer's comments	2	25 January 2010
Research Interest Slip	3	19 July 2010
Shortened LEDS Interview		31 July 2010

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review



**National Research Ethics Service**

**NRES Committee South Central - Berkshire**

Bristol REC Centre Whitefriars  
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Bristol  
BS1 2NT

Tel: 0117 3421389  
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27March2012

Miss Lindsay Smith  
Post Graduate Researcher  
King's College London  
Institute of Psychiatry  
P048; Addiction Sciences Building  
4 Windsor Walk, London  
SE5 8AF

Dear Miss Smith,

**Title: the role of socio-cultural differences in care-giving processes in psychosis**

**REC reference:** 10/H0505/79  
**Protocol number:** N/A  
**Amendment number:** Substantial Amendment 2:

- 1. Addition of a Care-giving Relationship Questionnaire.**
- 2. Extension of recruitment to include the Central and North West London NHS Trust.**

**Amendment date:** 08 March 2012

The above amendment was reviewed on 22 March 2012 by the Sub-Committee in correspondence.

**Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

**Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Medina-Pradas et al. 2011 Paper		
Questionnaire: Revised CRQ inc. warmth items	1	06 March 2012
Questionnaire: CRQ - Carer Version	1	01 October 2010
Questionnaire: CRQ - Patient Version	1	01 October 2010
Notice of Substantial Amendment (non-CTIMPs)		08 March 2012
Covering Letter		06 March 2012

### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

### R&D approval

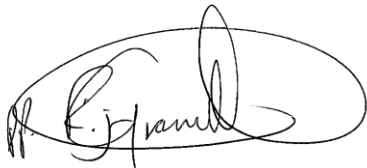
All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**10/H0505/79: Please quote this number on all correspondence**

Yours sincerely,



**Mr David Carpenter**  
**Chair**

E-mail: [scsha.berksrec@nhs.net](mailto:scsha.berksrec@nhs.net)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Ms Jenny Liebscher, SLaM/IoP R&D Office, R&D Governance and Delivery Manager*



REC/Ref. 10/H0505/79

Date XXXXXX

Dear \_\_\_\_\_,

**TAKING PART IN SCIENTIFIC RESEARCH**

We would like to inform you about a new research project examining the opinions of people who support individuals with mental health problems.

We've enclosed an information sheet about the project and we invite you to consider whether you might like to take part.

The study would require a couple of hours of your time and would involve completing some questionnaires and interviews. You will be reimbursed for your time.

If you would like to hear more, please fill in the interest slip enclosed and return in the free, stamped, addressed envelope provided. A member of the research team will contact you to explain the project in detail and answer any questions that you may have.

Alternatively, you can contact the team directly by email or telephone:

Lindsay Smith

[Lindsay.smith@kcl.ac.uk](mailto:Lindsay.smith@kcl.ac.uk)

02078480427

Please note that this is a voluntary study. There is no obligation to take part. You are free to withdraw at any time and without giving a reason. This will not affect any services you receive from the mental health team in any way.

Thank you and best wishes,

[XXXXClinicalTeamRepresentativeXXX]





University of London

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REC/Ref. 10/H0505/79

**RESEARCH INTEREST SLIP**

If you would like hear more about the research project, CAREGIVING PROCESSES IN ADULTHOOD, please fill out the contact details listed below and return in the free, stamped addressed envelope provided.

FIRST NAME and SURNAME

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DATE OF BIRTH (DD/MM/YY):

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GENDER:

☐ MALE ☐ FEMALE

ADDRESS:

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POSTCODE/ TOWN:

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EMAIL:

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MOBILE PHONE:

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LANDLINE:

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When [day and time] is it best to contact you by phone:\_\_\_

## INFORMATION SHEET FOR PARTICIPANTS

Carer Information Sheet: Study 2

Version 5: 04/09/10

REC/Ref. 10/H0505/79



University of London

Institute of Psychiatry

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TEL: 02078480427

[Lindsay.smith@kcl.ac.uk](mailto:Lindsay.smith@kcl.ac.uk)

[Juliana.1.onwumere@kcl.ac.uk](mailto:Juliana.1.onwumere@kcl.ac.uk)

### YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

#### CARE-GIVING PROCESSES IN ADULTHOOD

##### What am I being asked to do?

You have been invited to take part in a research study that is being conducted in part fulfillment of an educational qualification. Before you decide if you would like to participate we want to make sure that you understand the purpose of this study and what it would involve for you.

##### What is the purpose of the study?

According to the latest UK government figures, almost 7 million people in the UK provide care-giving support for friends or relatives with mental health problems. There is a need to improve our understanding of how different people cope with their role. We hope that the results of this study will prove useful in developing targeted support services for adults with mental health difficulties and their families.

##### Why have I been asked to take part?

You have been invited to take part because we are interested in your experiences as a care-giver (someone who provides help and support to a close relative or friend). We would like to know more about your attitudes towards mental health issues, how care-giving has affected you mentally and physically and your views on the relationship you hold with your friend or relative. Your friend or relative will also be invited to take part in the study.

##### Do I have to take part?

No. It is up to you to decide whether or not to take part.

If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the support you, or your friend or relative, receive from clinical services in any way.

##### What would I have to do within the study?

You will be asked to take part in an informal discussion about the relationship you have with the person for whom you provide care-giving support. The interview will include questions about their mental health difficulties, how it may have affected your life and theirs, your reactions to the illness, as well as thoughts and feelings about the relationship and the future.

This will be organized at a convenient time and location for you by the Principal researcher, Lindsay Smith.

In addition, you will be asked to complete a series of questionnaires that focus on your attitudes to care-giving, how you cope with things in your life, what support systems you have available and how you have been feeling mentally and physically. The questionnaires can be completed easily at home, at your local NHS Trust or at the Institute of Psychiatry, in Camberwell.

The interview and questionnaires should take a total of approximately 2.5 hours to complete [60 minutes for the interview; 90 minutes for the questionnaires]. You will be encouraged to take breaks whenever needed.

We will also ask your friend or relative to share their impressions on your relationship and to complete similar questionnaires on how they have been feeling recently and how they cope.

**Will I be reimbursed for any expenses?**

Yes, all travel expenses will be reimbursed. In addition, everyone will receive £10 by way of thanks for their time.

**Will my information be confidential?**

All of your answers to the questionnaires will be kept anonymous and will be identifiable only by a number, not by your name. The information you provide will not be shared with your relative or friend that takes part. With your consent we will inform your friend/relative's clinical team that they are taking part in the study. The information you give will usually be available only to the research team. However, the researcher will share with your friend/relative's clinical team any important information that is relevant to the support that he/she and you may receive from services. Storage and work on clinical data will always be in accordance with the current ethical guidelines

**What are the possible risks of taking part?**

It is not expected that participation in the study has any risks. However, if you find any of the questions asked upsetting and would like to talk about this, please talk to your care-coordinator or doctor, or contact the researcher (see below).

**What are the possible benefits to taking part?**

We do not expect the study to help directly with the service or care that you or your friend/relative receives, although some people report finding answering the questions useful and interesting. We hope that the research will help to improve services we offer to other people in the future.

**What would happen if I did not want to continue with the study?**

Participation in this study is entirely voluntary. You may withdraw your consent at any time during the study. You do not need to explain or justify your reasons for withdrawing, and it will not have any adverse effects on you or your relative. If you wish your data will then be destroyed. However, once anonymised data has been transferred to the database it will no longer be possible to withdraw your data or samples as it will not convey participant identity.

**What should I do if I have any problems?**

If you are concerned about any aspect of this study, please speak to the researcher to clarify any queries. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital or clinic.

Although we do not expect the study to have any risks, in the event that you are harmed due to the research, and this is due to someone's negligence, then you may have grounds for a legal action for compensation against King's College London but you may have to pay for your legal costs. The normal NHS complaints mechanisms will still be available to you (if appropriate).

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable ethical opinion for conduct by the Berkshire Research Ethics Committee.

**How do I contact the research team?**

Principal Researcher: Lindsay Smith  
Email: [lindsay.smith@kcl.ac.uk](mailto:lindsay.smith@kcl.ac.uk)  
Phone: **02078480427**

Post: Institute of Psychiatry,  
PO48, Addiction Sciences Building  
4 Windsor Walk  
SE5 8AF

**Further questions?**

If you have any further questions, please do not hesitate to contact us. We are happy to answer all the questions you may have concerning this study.

**Thank you for reading this information sheet.**

## INFORMATION SHEET FOR PARTICIPANTS

Service User Information Sheet: Study 2    Version 5: 04/09/10    REC/Ref. 10/H0505/79



University of London

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[Juliana.1.onwumere@kcl.ac.uk](mailto:Juliana.1.onwumere@kcl.ac.uk)

### YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

#### CARE-GIVING PROCESSES IN ADULTHOOD

##### What am I being asked to do?

You are being invited to take part in a research study that is being conducted in part fulfillment of an educational qualification. Before you decide if you would like to participate we want to make sure that you understand the purpose of this study and what it would involve for you.

##### What is the purpose of the study?

According to the latest UK government figures, almost 7 million people in the UK provide care-giving support for friends or relatives with mental health problems. There is a need to improve our understanding of how different people cope with their role. We hope that the results of this study will prove useful in developing targeted support services for adults with mental health difficulties and their families.

##### Why have I been asked to take part?

You have been invited to take part through your clinical service because we are interested in the support systems available to individuals with mental health difficulties and the family or friends who provide them with regular help and support. In particular, we are interested in your attitudes towards mental health issues, your general health and wellbeing, your relationships with close friends or family members and your experiences with mental health difficulties.

We are inviting people who have been referred to and are receiving treatment from your team, along with a close relative or friend who provides them with regular help and support.

##### Do I have to take part?

No. It is up to you to decide whether or not to take part.

If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the care you receive from your team in any way.

##### What would I have to do within the study?

You will be asked to complete two short interviews. The first will explore how you have been feeling recently (whether you have been experiencing any signs or symptoms of illness). The second will ask about your weekly activities. In addition, you will be asked to complete a series of questionnaires about your views on mental health issues, how you cope with things in your life and your feelings about the relationship that you have with the person that supports you most, as well as other services. The questionnaires can be completed easily at home, at your local NHS Trust or at the Institute of Psychiatry, in Camberwell.

The interviews and questionnaires should take approximately 2 hours to complete (40 minutes for the interviews and 90 minutes for the questionnaires)

We will also ask your friend or relative to share their impressions on your relationship and to complete similar interviews and questionnaires on how they have been feeling recently and how they cope.

**Will I be reimbursed for any expenses?**

Yes, all travel expenses will be reimbursed. In addition, everyone will receive £10 by way of thanks for their time.

**Will my information be confidential?**

All of your answers to the questionnaires will be kept anonymous and will be identifiable only by a number, not by your name. The information you provide will not be shared with your relative or friend that takes part. With your consent we will inform your clinical team that you are taking part in the study. The information you give will usually be available only to the research team. However, the researcher will share with your clinical team any important information that is relevant to the care you receive. Storage and work on clinical data will always be in accordance with the current ethical guidelines

**What are the possible risks of taking part?**

It is not expected that participation in the study has any risks. However, if you find any of the questions asked upsetting and would like to talk about this, please talk to your care-coordinator or doctor, or contact the researcher (see below).

**What are the possible benefits to taking part?**

We do not expect the study to help directly with your care, although some people report finding answering the questions useful and interesting. We hope that the research will help to improve services we offer to other people in the future.

**What would happen if I did not want to continue with the study?**

Participation in this study is entirely voluntary. You may withdraw your consent at any time during the study. You do not need to explain or justify your reasons for withdrawing, and it will not have any adverse effects on you or your relative. If you wish your data will then be destroyed. However, once anonymised data has been transferred to the database it will no longer be possible to withdraw your data or samples as it will not convey participant identity.

**What should I do if I have any problems?**

If you are concerned about any aspect of this study, please speak to the researcher to clarify any queries. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital or clinic.

Although we do not expect the study to have any risks, in the event that you are harmed due to the research, and this is due to someone's negligence, then you may have grounds for a legal action for compensation against King's College London but you may have to pay for your legal costs. The normal NHS complaints mechanisms will still be available to you (if appropriate).

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable ethical opinion for conduct by the Berkshire Research Ethics Committee.

**How do I contact the research team?**

Principal Researcher: Lindsay Smith  
Email: [lindsay.smith@kcl.ac.uk](mailto:lindsay.smith@kcl.ac.uk)  
Phone: **02078480427**

Post: Institute of Psychiatry,  
PO48, Addiction Sciences Building  
4 Windsor Walk  
SE5 8AF

**Further Questions?**

If you have any further questions, please do not hesitate to contact us. We are happy to answer all the questions you may have concerning this study.

**Thank you for reading this information sheet**

**CONSENT FORM FOR PARTICIPANTS**

Carer

Version 6: 04/01/11

REC/Ref. 10/H0505/79

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: CARE-GIVING PROCESSES IN ADULTHOOD

- Thank you for considering to take part in this research.
- If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep.

Please initial each box:

1. *I understand that if I decide at any time during the research that I no longer wish to participate in this project, I can notify the researchers involved and be withdrawn from it immediately.* ☐
2. *I understand that a decision to withdraw at any time, or a decision not to take part, will not affect support that I or my friend/relative receive from clinical services in any way.* ☐
3. *I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.* ☐
4. *I consent to be contacted regarding future studies. I understand that this does not oblige me in any way to take part in these studies.* ☐

Participant's Statement:

I \_\_\_\_\_ [PRINT NAME]

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed \_\_\_\_\_

Date \_ / \_ / \_

Investigator's Statement:

I \_\_\_\_\_

confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the volunteer.

Signed \_\_\_\_\_

Date \_ / \_ / \_



**CONSENT FORM FOR PARTICIPANTS**

Service User

Version 6: 04/01/11

REC/Ref. 10/H0505/79

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: CARE-GIVING PROCESSES IN ADULTHOOD

- Thank you for considering to take part in this research.
- If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep.

Please initial each box:

1. *I understand that if I decide at any time during the research that I no longer wish to participate in this project, I can notify the researchers involved and be withdrawn from it immediately.*

☐

2. *I understand that a decision to withdraw at any time, or a decision not to take part, will not affect the care I receive from my clinical team in any way.*

☐

3. *I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.*

☐

4. *I consent to accessing of my clinical records by the chief investigator listed below for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with ethical guidelines and the provisions of the Data Protection Act 1998.*

☐

5. *I consent to be contacted regarding future studies. I understand that this does not oblige me in any way to take part in these studies.*

☐

Participant's Statement:

I \_\_\_\_\_ [PRINT NAME]

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed \_\_\_\_\_

Date \_ / \_ / \_

Investigator's Statement:

I \_\_\_\_\_

confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the volunteer.

Signed \_\_\_\_\_

Date \_ / \_ / \_

ID \_\_\_\_\_

Date of Completion: \_\_/\_\_/\_\_

**1. DEMOGRAPHIC QUESTIONNAIRE**

- 1.1** This study is particularly interested in ethnic and cultural differences in people's experiences of mental health issues and care-giving. To help us understand a little more about your family background, please indicate the country of birth and ethnicity of your parents and grandparents.

If your relatives were born outside the UK, please also indicate the total amount of time that they have spent living in Britain:

	Country of Birth	Ethnicity	If <u>NOT</u> born in the UK, Total number of <u>years</u> spent living in the UK
<b>MOTHER</b>			
<b>FATHER</b>			
<b>GRANDMOTHER (maternal)</b>			
<b>GRANDFATHER (maternal)</b>			
<b>GRANDMOTHER (paternal)</b>			
<b>GRANDFATHER (paternal)</b>			

**EDUCATION AND EMPLOYMENT**

- 1.2** Please indicate the number of years in which you remained in full time education: \_

- 1.3** Please indicate the highest level of education achieved: (please circle or \* appropriate)

No qualifications  
 GCSE/O' levels or equivalent  
 A' levels or equivalent  
 B. Tecs/NVQs or equivalent  
 First Degree (e.g BA, BSc)  
 Higher Degree (e.g MA, PhD, PGCE)

For any other UK or International qualifications, please specify \_\_\_\_\_

- 1.4** Do you have any of the following professional qualifications? (please circle or \* appropriate)

No Professional Qualifications  
 Qualified Teacher Status (for schools)

Qualified Medical Doctor  
 Qualified Dentist  
 Qualified Nurse, Midwife, Health Visitor

**1.5 Are you currently employed?** (please circle or \* all that are appropriate)

Student  
 In part-time employment  
 In full-time employment  
 Self-employed/family worker  
 Apprentice/trainee  
 Unemployed/Looking for a job  
     For how long have you been unemployed? \_\_\_\_\_ [months/weeks]  
 On sick leave/incapacity benefit  
     For how long have you been on leave \_\_\_\_\_ [months/weeks]  
 Retired  
 Volunteering  
 Never had a job  
 Other (please specify) \_\_\_\_\_

**1.6 Please can you provide us with an indication of your total income PER WEEK (before tax)?**

(tick as appropriate)

PER WEEK	
Nil or loss	
£1 - £79	
£80-£149	
£150-£229	
£230-£329	
£330-£459	
£460 - £709	
£710 or more	

**LIVING ARRANGEMENTS**

**1.7 In which London Borough do you currently live?** \_\_\_\_\_

**1.8 Please indicate whether you own or rent your current accommodation:**

Owned outright  
 Owned with mortgage or loan  
 Part rented/part mortgage  
 Rented accommodation  
 Social housing  
 Sheltered accommodation  
 Live in household rent free

**1.9 For how many YEARS have you lived at your current address?** \_\_\_\_\_

**1.10 Please indicate with whom you are currently living (please circle or \* all that are appropriate):**

Living alone  
Living with siblings  
Living with parents  
Living with a partner or spouse  
Living with extended family members  
Living with friends  
Living in group-housing  
If living with DEPENDENT CHILDREN, how many: \_\_\_\_\_

**1.11 For the majority of time, how many people live with you in your home? \_\_\_\_**

**1.12 What is your current relationship status? (please circle or \* appropriate)**

Single  
In a recent relationship  
In a long- term relationship  
Married/in a civil partnership  
Divorced/Separated  
Widowed

**RELIGIOUS AFFILIATIONS**

**1.13 Do you regard yourself as belonging to any particular religion?**  
(please circle or \* appropriate)

None  
Church of England/Anglican  
Roman Catholic  
Presbyterian/Church of Scotland  
Methodist  
Baptist  
Pentecostal  
Congregational/United Reform/URC  
Buddhist  
Muslim/Islam  
Hindu  
Jewish  
Sikh  
Other (please specify) \_\_\_\_\_

**1.14 How often, if at all, do you attend religious services or meetings?**  
(please circle or \* appropriate)

Once a week or more  
Less often but at least once a month  
Less often but at least once a year  
Never or practically never

**1.15 How much difference would you say religious beliefs make to your life?**  
(please circle or \* appropriate)

A little difference  
Some difference  
A great difference  
None/no difference

**2. SF 36 – Health Survey**

**Ware & Sherbourne., 1992**

The following survey asks your views about your health – including how you feel and how well you are able to do your usual activities. Please answer every question by marking the answer as indicated. If you are unsure about how to answer a question please give the best answer you can.

**2.1 In general, would you say your health is: (circle ONE)**

Excellent.....	1
Very good .....	2
Good.....	3
Fair.....	4
Poor.....	5

**2.2. Compared to ONE YEAR AGO, how would you rate your general health now?**

Much better than a year ago .....	1
Somewhat better than a year ago .....	2
About the same as a year ago .....	3
Somewhat worse than a year ago .....	4
Much worse than a year ago .....	5

- 2.3** The following questions are about activities you might do during a typical day. Does your health now limit you in any of these activities? If so, how much?

(circle ONE number on each line)

Activities	Yes, limited a LOT	Yes, limited a LITTLE	No, NOT limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	1	2	3
Lifting or carrying groceries	1	2	3
Climbing several flights of stairs	1	2	3
Climbing one flight of stairs	1	2	3
Bending, kneeling or stooping	1	2	3
Walking more than a mile	1	2	3
Walking half a mile	1	2	3
Walking one hundred yards	1	2	3
Bathing or dressing yourself	1	2	3

- 2.4** During the PAST FOUR WEEKS, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle ONE number on each line)

	Yes	No
Cut down on the amount of time you spent on work or other activities	1	2
Accomplished less than you would like	1	2
Were limited in the kind of work or other activities	1	2
Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

- 2.5** During the PAST FOUR WEEKS, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle ONE number on each line)

	Yes	No
Cut down the amount of time you spent on work or other activities	1	2
Accomplished less than you would have liked	1	2
Didn't do work or other activities as carefully as usual	1	2

- 2.6 During the **PAST 4 WEEKS**, to what extent has your physical health or emotional health problems interfered with your normal social activities with family, friends, neighbours or groups?

(circle ONE)

Not at all .....	1
Slightly.....	2
Moderately.....	3
Quite a bit.....	4
Extremely.....	5

- 2.7 How much bodily pain have you had during the **PAST 4 WEEKS**?

None.....	1
Very mild.....	2
Mild.....	3
Moderate.....	4
Severe.....	5
Very Severe.....	6

- 2.8 During the **PAST 4 WEEKS**, how much did pain interfere with your normal work (including both work outside the home and housework)? (circle ONE)

Not at all .....	1
Slightly.....	2
Moderately.....	3
Quite a bit.....	4
Extremely.....	5

- 2.9** These questions are about how you feel and how things have been with you **DURING THE PAST 4 WEEKS**. For each question please give the one answer that comes closest to the way you have been feeling.

HOW MUCH OF THE TIME **DURING THE PAST 4 WEEKS**... (circle ONE no. on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	1	2	3	4	5	6
Have you been a very nervous person?	1	2	3	4	5	6
Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
Have you felt calm and peaceful?	1	2	3	4	5	6
Did you have a lot of energy?	1	2	3	4	5	6
Have you felt downhearted & low?	1	2	3	4	5	6
Did you feel worn out?	1	2	3	4	5	6
Have you been a happy person?	1	2	3	4	5	6
Did you feel tired?	1	2	3	4	5	6

- 2.10** **DURING THE PAST 4 WEEKS**, how much of the time have your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc)? (circle ONE)

- All of the time..... 1
- Most of the time..... 2
- Some of the time..... 3
- A little of the time..... 4
- None of the time..... 5

- 2.11** How **TRUE** or **FALSE** is each of the following statements to you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I seem to get ill more easily than other people	1	2	3	4	5
I am as healthy as anybody I know	1	2	3	4	5
I expect my health to get worse	1	2	3	4	5
My health is excellent	1	2	3	4	5



**3. THE PITTSBURGH SLEEP QUALITY INDEX (PSQI)****Buyse et al., 1989**

The following questions relate to your usual sleep habits DURING **THE PAST MONTH ONLY**. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions.

**DURING THE PAST MONTH:**

1. At what time do you usually go to bed? \_\_\_\_\_
2. How long (in minutes) has it taken you to fall asleep each night? \_\_\_\_\_
3. When have you usually gotten up in the morning? \_\_\_\_\_
4. How many hours of actual sleep do you get at night? (this may be different to the number of hours you spend in bed) \_\_\_\_\_

<b>5. DURING THE PAST MONTH, HOW OFTEN HAVE YOU HAD TROUBLE SLEEPING BECAUSE YOU....</b>	Not during the past month (1)	Less than once a week (2)	Once or twice a week (3)	Three or more times a week (4)
a. Cannot get to sleep within 30 minutes				
b. Wake up in the middle of the night or early in the morning				
c. Have to get up to use the bathroom				
d. Cannot breathe comfortably				
e. Cough or snore loudly				
f. Feel too cold				
g. Feel too hot				
h. Have had bad dreams				
i. Have pain				
j. Other reason(s), please describe, including how often you have had trouble sleeping because of this reason (s)				
6. During the past month, how often have you taken medicine (prescribed or over the counter) to help you sleep				
7. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?				
8. During the past month, how much of a problem has it been for you to keep up enthusiasm to get things done				
	Very Good (1)	Fairly Good (2)	Fairly Bad (3)	Very bad (4)
9. During the past month, how would you rate your sleep quality overall				

#### 4. **CENTRE FOR EPIDEMIOLOGICAL STUDIES DEPRESSION SCALE** **Radloff, 1977**

The 20 items below refer to how you have felt and behaved **DURING THE PAST WEEK**. Please circle the answer which best describes your experiences.

(circle ONE)

##### 4.1 **I was bothered by things that don't usually bother me.**

- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |

##### 4.2 **I did not feel like eating; my appetite was poor.**

- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |

##### 4.3 **I felt that I could not shake off the blues even with the help of my family or friends**

- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |

##### 4.4 **I felt that I was just as good as other people**

- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |

**4.5 I had trouble keeping my mind on what I was doing.**

Rarely or none of the time (<1 day) .....	1
Some or a little of the time (1-2 days) .....	2
Occasionally or a moderate amount of the time (3-4 days).....	3
Most or all of the time (5-7 days).....	4

**4.6. I felt depressed.**

Rarely or none of the time (<1 day) .....	1
Some or a little of the time (1-2 days) .....	2
Occasionally or a moderate amount of the time (3-4 days).....	3
Most or all of the time (5-7 days).....	4

**4.7 I felt everything I did was an effort.**

Rarely or none of the time (<1 day) .....	1
Some or a little of the time (1-2 days) .....	2
Occasionally or a moderate amount of the time (3-4 days).....	3
Most or all of the time (5-7 days).....	4

**4. 8 I felt hopeful about the future.**

Rarely or none of the time (<1 day) .....	1
Some or a little of the time (1-2 days) .....	2
Occasionally or a moderate amount of the time (3-4 days).....	3
Most or all of the time (5-7 days).....	4

- 4.9 I thought my life had been a failure. (circle ONE)**
- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |
- 4.10 I felt fearful. (circle ONE)**
- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |
- 4.11 My sleep was restless (circle ONE)**
- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |
- 4.12 I was happy. (circle ONE)**
- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |

- 4.13 I talked less than usual. (circle ONE)**
- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |
- 4.14 I felt lonely. (circle ONE)**
- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |
- 4.15 People were unfriendly. (circle ONE)**
- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |
- 4.16 I enjoyed life. (circle ONE)**
- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |

- 4.17 I had crying spells. (circle ONE)**
- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |
- 4.18 I felt sad. (circle ONE)**
- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |
- 4.19 I felt that people disliked me. (circle ONE)**
- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |
- 4.20 I could not get "going" . (circle ONE)**
- |   |   |
|---|---|
| Rarely or none of the time (<1 day) .....                     | 1 |
| Some or a little of the time (1-2 days) .....                 | 2 |
| Occasionally or a moderate amount of the time (3-4 days)..... | 3 |
| Most or all of the time (5-7 days).....                       | 4 |

**5. BRIEF-COPE INVENTORY****Carver, 1997**

\*\*\*\*Please note that the items in this scale have been adapted from the B-COPE, Carver 1997\*\*\*\*

This section asks how you have typically tried to deal with difficulties you, a friend, partner or relative may be experiencing. Below is a list of things you may have done. Please decide if you have used each strategy **in the LAST 3 MONTHS** and if so how often you have used it.

1	I have never done this
2	I have rarely done this
3	I have sometimes done this
4	I have done this a lot

**HOW OFTEN HAVE YOU:-**

1	Gone to the cinema or watched TV, to think about the problem less	1	2	3	4
2	Drank alcohol or took drugs in order to think about the problem less	1	2	3	4
3	Sought God's help	1	2	3	4
4	Talked to someone about how you felt	1	2	3	4
5	Made a plan of action	1	2	3	4
6	Put aside other activities to concentrate on the problem	1	2	3	4
7	Looked for something good in what has happening	1	2	3	4
8	Made fun of the problem	1	2	3	4
9	Pretended the problem hadn't really happened	1	2	3	4
10	Given up your attempts to get what you wanted	1	2	3	4
11	Let your feeling out about the problem	1	2	3	4
12	Taken alcohol or drugs to help you get through the problem	1	2	3	4
13	Turned to work or other substitute activities to take your mind off the problem	1	2	3	4
14	Tried to find comfort in your religion	1	2	3	4
15	Just gave up trying to solve the problem	1	2	3	4
16	Made jokes about the problem	1	2	3	4
17	Learned to live with the problem	1	2	3	4
18	Forced yourself to wait for the right time to do something about the problem	1	2	3	4
19	Taken additional action to try and get rid of the problem	1	2	3	4
20	Kept yourself from getting distracted by other things	1	2	3	4
21	Made sure you did not make matters worse by acting too soon	1	2	3	4
22	Asked people who have had similar experiences what they did	1	2	3	4
23	Tried to see the problem in a different light, to make it seem more positive	1	2	3	4
24	Tried to get emotional support from friends or relatives	1	2	3	4
25	Accepted that the problem had happened and that nothing can be done to change it	1	2	3	4
26	Got upset and let your emotions out	1	2	3	4
27	Refused to believe the problem had happened	1	2	3	4
28	Tried to get advice from someone about what to do	1	2	3	4
29	Tried to come up with a strategy about what to do	1	2	3	4
30	Concentrated your efforts on doing something about the problem	1	2	3	4

**6. BRIEF ILLNESS PERCEPTIONS QUESTIONNAIRE****Broadbent et al., 2006**

Similarly, for the following questions, **please circle the number on the scale** that best corresponds to the views you currently hold about your friend/relative's mental health issues:

**1. How much do their problems/illness affect your life?**

No affect at all	1	2	3	4	5	6	7	8	9	10	Severely affects my life
------------------	---	---	---	---	---	---	---	---	---	----	--------------------------

**2. How long do you think their problems/illness will continue?**

A very short time	1	2	3	4	5	6	7	8	9	10	Forever
-------------------	---	---	---	---	---	---	---	---	---	----	---------

**3. How much control do you feel he/she has over their problems/illness?**

No control at all	1	2	3	4	5	6	7	8	9	10	A great deal of control
-------------------	---	---	---	---	---	---	---	---	---	----	-------------------------

**4. How much do you think his/her treatment can help their problems/illness?**

Not at all helpful	1	2	3	4	5	6	7	8	9	10	Extremely helpful
--------------------	---	---	---	---	---	---	---	---	---	----	-------------------

**5. How much does he/she experience symptoms from their problems/illness?**

No symptoms at all	1	2	3	4	5	6	7	8	9	10	Many severe symptoms
--------------------	---	---	---	---	---	---	---	---	---	----	----------------------

**6. How concerned are you about their problems/illness?**

Not concerned at all	1	2	3	4	5	6	7	8	9	10	Extremely concerned
----------------------	---	---	---	---	---	---	---	---	---	----	---------------------

**7. How well do you feel that you understand their problems/illness?**

Don't understand at all	1	2	3	4	5	6	7	8	9	10	Understand it completely
-------------------------	---	---	---	---	---	---	---	---	---	----	--------------------------



8. How much do their problems/illness affect you emotionally? (e.g does it make you angry, scared, upset or depressed?)

Not at all affected emotionall	1	2	3	4	5	6	7	8	9	10	Extremely affected emotionally
--------------------------------------	---	---	---	---	---	---	---	---	---	----	--------------------------------------

9. How much control do you feel that YOU have over their problems/illness?

No control at all	1	2	3	4	5	6	7	8	9	10	A great deal of control
----------------------	---	---	---	---	---	---	---	---	---	----	-------------------------------

Please list in rank order the **three** most important factors that you believe caused **his/her problems/illness**. With number 1 being the most influential cause.

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

**7. EXPERIENCE OF CAREGIVING INVENTORY****Smukler et al. 1996**

The following questions commonly apply to individuals who provide help and support for people experiencing mental health difficulties and those who care for individuals with more severe illness. We would like you to read each one and decide how often it has applied to you over the **past one month**.

**During the past month** how often have you thought about:

		NEVE R	RAREL Y	SOME TIMES	OFTE N	NEARL Y ALWAY S
1	Your covering up his/her problems/illness	1	2	3	4	5
2	Feeling unable to tell anyone of the problems/illness	1	2	3	4	5
3	His/her difficulty in looking after money	1	2	3	4	5
4	Having to support him/her	1	2	3	4	5
5	What life s/he may have been leading without these problems	1	2	3	4	5
6	His/her risk of committing suicide	1	2	3	4	5
7	That you have learnt a lot about yourself	1	2	3	4	5
8	That you have contributed to others understanding of the problems/illness he/she is dealing with	1	2	3	4	5
9	Being able to do the things you want to do	1	2	3	4	5
10	How health professionals do not take you seriously	1	2	3	4	5
11	His/her dependence on you	1	2	3	4	5
12	Helping him/her to fill in the day	1	2	3	4	5
13	That you have contributed to his/her wellbeing	1	2	3	4	5
14	That s/he makes a valuable contribution to the household	1	2	3	4	5
15	The effect on your finances if s/he becomes more seriously ill	1	2	3	4	5
16	Dealing with psychiatrists	1	2	3	4	5
17	Him/her always being at the back of your mind	1	2	3	4	5
18	Whether you have done something to make him/her have these problems/this illness	1	2	3	4	5
19	That s/he has shown strengths in coping with his/her problems/ illness	1	2	3	4	5
20	That you have become more confident in dealing with others	1	2	3	4	5
21	How family members do not understand your situation	1	2	3	4	5
22	That s/he is good company	1	2	3	4	5
23	That you have become more understanding of others with problems	1	2	3	4	5
24	How s/he thinks a lot about death	1	2	3	4	5

		NEVER	RARELY	SOMETIMES	OFTEN	NEARLY ALWAYS
25	His/her lost opportunities	1	2	3	4	5
26	How to deal with mental health professionals	1	2	3	4	5
27	Feeling unable to have visitors at home	1	2	3	4	5
28	How s/he gets on with other family members	1	2	3	4	5
29	Backing him/her up when he runs out of money	1	2	3	4	5
30	How family members do not understand his/her problems or illness	1	2	3	4	5
31	How s/he deliberately attempts to harm himself	1	2	3	4	5
32	That you have become closer to some of your family	1	2	3	4	5
33	That you have become closer to friends	1	2	3	4	5
34	That you share some of his/her interests	1	2	3	4	5
35	That you feel useful in your relationship with him/her	1	2	3	4	5
36	That health professionals do not understand your situation	1	2	3	4	5
37	Whether s/he will ever be fully well again	1	2	3	4	5
38	Feeling the stigma of having a relative with mental health issues	1	2	3	4	5
39	How to explain his/her problems/ illness to others	1	2	3	4	5
40	Others leaving home because of the effect of his/her problems or illness	1	2	3	4	5
41	Setting him/her up in accommodation	1	2	3	4	5
42	How to make complaints about his/her support services	1	2	3	4	5
43	That you have met helpful people	1	2	3	4	5
44	That you have discovered strengths in yourself	1	2	3	4	5
45	Feeling unable to leave him/her home alone	1	2	3	4	5
46	The effect of the problems/ illness on children in the family	1	2	3	4	5
47	The problems/ illness causing a family breakup	1	2	3	4	5
48	Him keeping bad company	1	2	3	4	5
49	How his/her problems effect special family events	1	2	3	4	5

50	Finding out how hospitals or mental health services work	1	2	3	4	5
51	Doctors knowledge of the services available to families	1	2	3	4	5
52	The difficulty getting information about his/her problems or illness	1	2	3	4	5

**During the past month how often have you thought about him/her being:**

		NEVER	RARELY	SOME TIMES	OFTEN	NEARLY ALWAYS
53	Moody	1	2	3	4	5
54	Unpredictable	1	2	3	4	5
55	Withdrawn	1	2	3	4	5
56	Uncommunicative	1	2	3	4	5
57	Not interested	1	2	3	4	5
58	Slow at doing things	1	2	3	4	5
59	Unreliable about things	1	2	3	4	5
60	Indecisive	1	2	3	4	5
61	Irritable	1	2	3	4	5
62	Inconsiderate	1	2	3	4	5
63	Behaving in a reckless way	1	2	3	4	5
64	Suspicious	1	2	3	4	5
65	Embarrassing in appearance	1	2	3	4	5
66	Behaving in a strange way	1	2	3	4	5

**8. THE MULTI-GROUP ETHNIC IDENTITY MEASURE (MEIM),****Phinney, 1992**

Please indicate to what extent you agree or disagree with the following statements about your cultural background and ethnic identity.

		<b>Strongly Agree (1)</b>	<b>Agree (2)</b>	<b>Disagree (3)</b>	<b>Strongly Disagree (4)</b>
1	I have spent time trying to find out more about my cultural background/ethnic group, such as its history, traditions, and customs				
2	I am active in organisations or social groups that include mostly members of my own ethnic group				
3	I have a clear sense of my cultural or ethnic background and what it means for me				
4	I think a lot about how my life will be affected by my ethnic group membership				
5	I am happy that I am a member of the group I belong to				
6	I have a strong sense of belonging to my own ethnic group				
7	I understand pretty well what my ethnic group membership means to me				
8	In order to learn more about my ethnic or cultural background, I have often talked to other people about my ethnic group				
9	I have a lot of pride in my ethnic group				
10	I participate in cultural practices of my own group, such as special food, music, or customs				
11	I feel a strong attachment towards my own cultural identity/ethnic group				
12	I feel good about my cultural or ethnic background				

## 9. Care-giving Relationships Questionnaire

Mental health difficulties can cause problems and stress not only for the individuals experiencing them, but also for members of their family and friends.

Different families respond to difficulties in different ways. At times relationships can be warm and supportive but naturally there are also occasions when people get frustrated and critical of one and another.

You will have already discussed with us a person with whom you spend significant amounts of time and whom provides you with the greatest help and support. This person will also be taking part in the research.

The following questionnaire is interested in experiences and exchanges you may have had with this person **DURING THE PAST MONTH**.

Please consider each of the questions carefully. The information provided will be kept **strictly confidential**.

### **RESPONSES SHOULD BE GIVEN BY CIRCLING AN APPROPRIATE NUMBER FROM 1-10**

#### 1. How **PROTECTIVE** has she/he been of you?

[not at all] 1 2 3 4 5 6 7 8 9 10 [very protective]  
protective

#### 2. How much has s/he **WORRIED** about you?

[not at all] 1 2 3 4 5 6 7 8 9 10 [very worried]  
worried

#### 3. Have you felt **LOVED** by him/her?

[not at all] 1 2 3 4 5 6 7 8 9 10 [completely loved]  
loved

#### 4. How much does s/he **LIKE TO SPEND TIME** and do things with you?

[None 1 2 3 4 5 6 7 8 9 10 [all of the time]  
of the time]

5. How UPSET has s/he got if you were having trouble?

[not at all] 1 2 3 4 5 6 7 8 9 10 [very upset]  
upset

6. How CRITICAL do you think S/HE has been of YOU?

[not at all] 1 2 3 4 5 6 7 8 9 10 [very critical]  
Critical

7. How CARING has s/he been of you?

[not at all] 1 2 3 4 5 6 7 8 9 10 [very caring]  
caring

8. How WARM has s/he been towards you?

[not at all] 1 2 3 4 5 6 7 8 9 10 [very warm]  
warm

**10. FAMILY ATTITUDE SCALE****Kavanagh et al., 1997**

Providing caring support for a friend or relative who is experiencing mental health difficulties can raise many different feelings and thoughts. Please indicate in the following questions how you have been feeling about your friend or relative over the PAST MONTH.

**Please be assured that your answers are completely confidential.**

**Please circle as appropriate**

		<b>Every day</b>	<b>Most days</b>	<b>Some days</b>	<b>Very rarely</b>	<b>Never</b>
1	It is good to have him/her around	1	2	3	4	5
2	S/he makes me feel drained	1	2	3	4	5
3	S/he ignores my advice	1	2	3	4	5
4	S/he is really hard to take	1	2	3	4	5
5	I shout at him/her	1	2	3	4	5
6	I wish s/he were not here	1	2	3	4	5
7	I feel that s/he is driving me crazy	1	2	3	4	5
8	I lose my temper with him/her	1	2	3	4	5
9	S/he is easy to get along with	1	2	3	4	5
10	I am sick of having to look after him/her	1	2	3	4	5
11	S/he deliberately causes me problems	1	2	3	4	5
12	I enjoy being with him/her	1	2	3	4	5
13	S/he is a real burden	1	2	3	4	5
14	I argue with him/her	1	2	3	4	5
15	I feel very close to him/her	1	2	3	4	5
16	I can cope with him/her	1	2	3	4	5
17	Living with him/her is too much for me	1	2	3	4	5
18	S/he is infuriating	1	2	3	4	5
19	I find myself saying nasty or sarcastic things to him/her	1	2	3	4	5
20	S/he appreciates what I do for him/her	1	2	3	4	5
21	I feel that s/he is becoming easier to live with	1	2	3	4	5
22	I wish s/he could leave me alone	1	2	3	4	5
23	S/he takes me for granted	1	2	3	4	5
24	S/he can control himself/herself	1	2	3	4	5
25	S/he is hard to get close to	1	2	3	4	5
26	I feel that s/he is becoming harder to love	1	2	3	4	5
27	I feel very frustrated with him/her	1	2	3	4	5
28	S/he makes a lot of sense	1	2	3	4	5
29	I feel disappointed with him/her	1	2	3	4	5
30	She tries to get along with me	1	2	3	4	5



**11. EMOTIONAL REACTIVITY SCALE****Docherty et al., 2009**

This questionnaire deals with a number of common behaviours and self-perceptions. For each question you should tick the response which best describes you and your behaviours.

		Never or almost Never (1)	Seldom (2)	Occasionall y (3)	Frequentl y (4)	Always, or almost always (5)
1	Criticism upsets me					
2	Music affects me emotionally					
3	I am easily upset					
4	My mood is affected by the weather					
5	I worry about bad things that might happen					
6	I care whether people like me					
7	Loud noises bother me					
8	I feel hurt if someone I know ignores me					
9	I have big ups and downs in mood					
10	My eyes are drawn to beautiful colours					
11	I get very upset when bad things happen to my friends					
12	I experience very intense emotions					
13	Other people's moods affect me					

**12. AROUSAL PREDISPOSITION SCALE****Coren, 1988**

This questionnaire deals with a number of common behaviours and self-perceptions. For each statement you should tick the response which best describes you and your behaviours.

		<b>Never or almost Never</b>	<b>Seldom</b>	<b>Occasionally</b>	<b>Frequently</b>	<b>Always, or almost always</b>
		<b>(1)</b>	<b>(2)</b>	<b>(3)</b>	<b>(4)</b>	<b>(5)</b>
<b>1</b>	I am a calm person					
<b>2</b>	I get flustered if I have several things to do at once					
<b>3</b>	Sudden changes of any kind produce an immediate emotional effect on me					
<b>4</b>	Strong emotions carry over for one or two hours after I leave the situation which caused them					
<b>5</b>	I am restless and fidgety					
<b>6</b>	My mood is quickly influenced by entering new places					
<b>7</b>	I get excited easily					
<b>8</b>	I find that my heart keeps beating fast for a while after I have been 'stirred up'					
<b>9</b>	I can be emotionally moved by what other people consider simple things					
<b>10</b>	I startle easily					
<b>11</b>	I am easily frustrated					
<b>12</b>	I tend to remain excited or moved for a long period of time after seeing a good movie					

**13. BRIEF CORE SCHEMA SCALE****Fowler et al., 2006****BELIEFS ABOUT SELF AND OTHERS**

This questionnaire lists beliefs that people can hold about themselves or other people. Please indicate whether you hold each belief by CIRCLING NO OR YES. **IF YOU TICK YES THEN PLEASE ALSO** indicate how strongly you hold it BY **CIRCLING A NUMBER** (1-4). Try to judge the beliefs on how you have generally, over time, viewed yourself and others. Do not spend too long on each belief.

			BELIEVE IT SLIGHTLY	BELIEVE IT MODERATELY	BELIEVE IT VERY MUCH	I BELIEVE IT TOTALLY
<b>MYSELF</b>						
I am unloved	NO	YES →	1	2	3	4
I am worthless	NO	YES →	1	2	3	4
I am weak	NO	YES →	1	2	3	4
I am vulnerable	NO	YES →	1	2	3	4
I am bad	NO	YES →	1	2	3	4
I am a failure	NO	YES →	1	2	3	4
I am respected	NO	YES →	1	2	3	4
I am valuable	NO	YES →	1	2	3	4
I am talented	NO	YES →	1	2	3	4
I am successful	NO	YES →	1	2	3	4
I am good	NO	YES →	1	2	3	4
I am interesting	NO	YES →	1	2	3	4
<b>OTHER PEOPLE</b>						
Other people are hostile	NO	YES →	1	2	3	4
Other people are harsh	NO	YES →	1	2	3	4
Other people are unforgiving	NO	YES →	1	2	3	4
Other people are bad	NO	YES →	1	2	3	4
Other people are devious	NO	YES →	1	2	3	4
Other people are nasty	NO	YES →	1	2	3	4
Other people are fair	NO	YES →	1	2	3	4
Other people are good	NO	YES →	1	2	3	4
Other people are trustworthy	NO	YES →	1	2	3	4
Other people are accepting	NO	YES →	1	2	3	4
Other people are supportive	NO	YES →	1	2	3	4
Other people are truthful	NO	YES →	1	2	3	4

\*\*\*\*\*

\*SF 36 - CARERS - Amended

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#### **\*physical functioning**

```

replace CSF36_3Vigorous =. if CSF36_3Vigorous!=1 &
CSF36_3Vigorous!=2 & CSF36_3Vigorous!= 3
replace CSF36_4Moderate=. if CSF36_4Moderate!=1 &
CSF36_4Moderate!=2 & CSF36_4Moderate!= 3
replace CSF36_5Lifting =. if CSF36_5Lifting!= 1 & CSF36_5Lifting!= 2
& CSF36_5Lifting!= 3
replace CSF36_5Climbing=. if CSF36_5Climbing!= 1 &
CSF36_5Climbing!= 2 & CSF36_5Climbing!= 3
replace CSF36_6Climbing1=. if CSF36_6Climbing1!= 1 &
CSF36_6Climbing1!= 2 & CSF36_6Climbing1!= 3
replace CSF36_7Bending=. if CSF36_7Bending!= 1 & CSF36_7Bending!= 2
& CSF36_7Bending!= 3
replace CSF36_8Walking=. if CSF36_8Walking!= 1 & CSF36_8Walking!= 2
& CSF36_8Walking!= 3
replace CSF36_9Walkinghalf=. if CSF36_9Walkinghalf!= 1 &
CSF36_9Walkinghalf!= 2 & CSF36_9Walkinghalf!= 3
replace CSF36_10Walking100=. if CSF36_10Walking100!= 1 &
CSF36_10Walking100!= 2 & CSF36_10Walking100!= 3
replace CSF36_11Bathing=. if CSF36_11Bathing!= 1 &
CSF36_11Bathing!= 2 & CSF36_11Bathing!= 3

gen physicalfnc_total = CSF36_3Vigorous + CSF36_4Moderate +
CSF36_5Lifting + CSF36_5Climbing + CSF36_6Climbing1 + CSF36_7Bending
+ CSF36_8Walking + CSF36_9Walkinghalf + CSF36_10Walking100 +
CSF36_11Bathing

```

#### **\*Role Phsyical**

```

replace CSF36_12phycutdown=. if CSF36_12phycutdown!= 1 &
CSF36_12phycutdown!= 2
replace CSF36_13phyaccomless=. if CSF36_13phyaccomless!= 1 &
CSF36_13phyaccomless!= 2
replace CSF36_14phylimitedwork=. if CSF36_14phylimitedwork!= 1 &
CSF36_14phylimitedwork!= 2
replace CSF36_15phydifficulty=. if CSF36_15phydifficulty!= 1 &
CSF36_15phydifficulty!= 2

gen rolephysc_total = CSF36_12phycutdown + CSF36_13phyaccomless +
CSF36_14phylimitedwork + CSF36_15phydifficulty

```

#### **\*Bodily Pain**

```

replace CSF36_20bodypain = . if CSF36_20bodypain!= 1 &
CSF36_20bodypain!= 2 & CSF36_20bodypain!= 3 & CSF36_20bodypain!= 4
& CSF36_20bodypain!= 5 & CSF36_20bodypain!= 6
replace CSF36_21painwork= . if CSF36_21painwork!= 1 &
CSF36_21painwork!= 2 & CSF36_21painwork!= 3 & CSF36_21painwork!= 4
& CSF36_21painwork!= 5

gen bodily_total = CSF36_20bodypain + CSF36_21painwork

```

**\* general health**

```
replace CSF36_1Ghealth=. if CSF36_1Ghealth!=1 & CSF36_1Ghealth!=2 &
CSF36_1Ghealth!=3 & CSF36_1Ghealth!=4 & CSF36_1Ghealth!=5
```

```
replace CSF36_1Ghealth=5 if CSF36_1Ghealth== 1
replace CSF36_1Ghealth=4 if CSF36_1Ghealth== 2
replace CSF36_1Ghealth=3 if CSF36_1Ghealth== 3
replace CSF36_1Ghealth=2 if CSF36_1Ghealth== 4
replace CSF36_1Ghealth=1 if CSF36_1Ghealth== 5
```

```
replace CSF36_32ill=. if CSF36_32ill!=1 & CSF36_32ill!=2 &
CSF36_32ill!=3 & CSF36_32ill!=4 & CSF36_32ill!=5
```

```
replace CSF36_33healthy=. if CSF36_33healthy!=1 &
CSF36_33healthy!=2 & CSF36_33healthy!=3 & CSF36_33healthy!=4 &
CSF36_33healthy!=5
```

```
replace CSF36_33healthy=5 if CSF36_33healthy== 1
replace CSF36_33healthy=4 if CSF36_33healthy== 2
replace CSF36_33healthy=3 if CSF36_33healthy== 3
replace CSF36_33healthy=2 if CSF36_33healthy== 4
replace CSF36_33healthy=1 if CSF36_33healthy== 5
```

```
replace CSF36_34healthworse=. if CSF36_34healthworse!=1 &
CSF36_34healthworse!=2 & CSF36_34healthworse!=3 &
CSF36_34healthworse!=4 & CSF36_34healthworse!=5
```

```
replace CSF36_35healthexcel=. if CSF36_35healthexcel!=1 &
CSF36_35healthexcel!=2 & CSF36_35healthexcel!=3 &
CSF36_35healthexcel!=4 & CSF36_35healthexcel!=5
```

```
replace CSF36_35healthexcel=5 if CSF36_35healthexcel== 1
replace CSF36_35healthexcel=4 if CSF36_35healthexcel== 2
replace CSF36_35healthexcel=3 if CSF36_35healthexcel== 3
replace CSF36_35healthexcel=2 if CSF36_35healthexcel== 4
replace CSF36_35healthexcel=1 if CSF36_35healthexcel== 5
```

```
gen genhealth_total = CSF36_1Ghealth+ CSF36_32ill + CSF36_33healthy+
CSF36_34healthworse + CSF36_35healthexcel
```

**\* Vitality**

```
replace CSF36_22fulloflife=. if CSF36_22fulloflife!=1 &
CSF36_22fulloflife!=2 & CSF36_22fulloflife!=3 &
CSF36_22fulloflife!=4 & CSF36_22fulloflife!=5 &
CSF36_22fulloflife!=6
```

```
replace CSF36_22fulloflife=6 if CSF36_22fulloflife==1
replace CSF36_22fulloflife=5 if CSF36_22fulloflife==2
replace CSF36_22fulloflife=4 if CSF36_22fulloflife==3
replace CSF36_22fulloflife=3 if CSF36_22fulloflife==4
replace CSF36_22fulloflife=2 if CSF36_22fulloflife==5
replace CSF36_22fulloflife=1 if CSF36_22fulloflife==6
```

```
replace CSF36_26energy=. if CSF36_26energy!=1 & CSF36_26energy!=2 &
CSF36_26energy!=3 & CSF36_26energy!=4 & CSF36_26energy!=5 &
CSF36_26energy!=6
```

```

replace CSF36_26energy=6 if CSF36_26energy==1
replace CSF36_26energy=5 if CSF36_26energy==2
replace CSF36_26energy=4 if CSF36_26energy==3
replace CSF36_26energy=3 if CSF36_26energy==4
replace CSF36_26energy=2 if CSF36_26energy==5
replace CSF36_26energy=1 if CSF36_26energy==6

replace CSF36_28wornout=. if CSF36_28wornout!=1 &
CSF36_28wornout!=2 & CSF36_28wornout!=3 & CSF36_28wornout!=4 &
CSF36_28wornout!=5 & CSF36_28wornout!=6

replace CSF36_30tired=. if CSF36_30tired!=1 & CSF36_30tired!=2 &
CSF36_30tired!=3 & CSF36_30tired!=4 & CSF36_30tired!=5 &
CSF36_30tired!=6

gen vitality_total = CSF36_22fulloflife + CSF36_26energy +
CSF36_28wornout + CSF36_30tired

*social functioning

replace CSF36_19social=. if CSF36_19social!=1 & CSF36_19social!=2
& CSF36_19social!=3 & CSF36_19social!=4 & CSF36_19social!=5

replace CSF36_19social= 5 if CSF36_19social==1
replace CSF36_19social= 4 if CSF36_19social==2
replace CSF36_19social= 3 if CSF36_19social==3
replace CSF36_19social= 2 if CSF36_19social==4
replace CSF36_19social= 1 if CSF36_19social==5

replace CSF36_31timesocial=. if CSF36_31timesocial!=1 &
CSF36_31timesocial!=2 & CSF36_31timesocial!=3 & CSF36_31timesocial!=4
& CSF36_31timesocial!=5

gen socfunct_total = CSF36_19social + CSF36_31timesocial

*Role emotional

replace CSF36_16emocutdown=. if CSF36_16emocutdown!= 1 &
CSF36_16emocutdown!=2
replace CSF36_17emoaccomless=. if CSF36_17emoaccomless!= 1 &
CSF36_17emoaccomless!=2
replace CSF36_18emocareful=. if CSF36_18emocareful!= 1 &
CSF36_18emocareful!=2

gen rolemo_total = CSF36_16emocutdown + CSF36_17emoaccomless +
CSF36_18emocareful

*mental health

replace CSF36_23nervous=. if CSF36_23nervous!=1 &
CSF36_23nervous!=2 & CSF36_23nervous!=3 & CSF36_23nervous!=4 &
CSF36_23nervous!=5 & CSF36_23nervous!=6
replace CSF36_24down=. if CSF36_24down!=1 & CSF36_24down!=2 &
CSF36_24down!=3 & CSF36_24down!=4 & CSF36_24down!=5 &
CSF36_24down!=6
replace CSF36_27downhearted=. if CSF36_27downhearted!=1 &
CSF36_27downhearted!=2 & CSF36_27downhearted!=3 &

```

```

CSF36_27downhearted!=4 & CSF36_27downhearted!=5 &
CSF36_27downhearted!=6

replace CSF36_25calm=. if CSF36_25calm!=1 & CSF36_25calm!=2 &
CSF36_25calm!=3 & CSF36_25calm!=4 & CSF36_25calm!=5 &
CSF36_25calm!=6

replace CSF36_25calm= 6 if CSF36_25calm== 1
replace CSF36_25calm= 5 if CSF36_25calm== 2
replace CSF36_25calm= 4 if CSF36_25calm== 3
replace CSF36_25calm= 3 if CSF36_25calm== 4
replace CSF36_25calm= 2 if CSF36_25calm== 5
replace CSF36_25calm= 1 if CSF36_25calm== 6

replace CSF36_29happy=. if CSF36_29happy!=1 & CSF36_29happy!=2 &
CSF36_29happy!=3 & CSF36_29happy!=4 & CSF36_29happy!=5 &
CSF36_29happy!=6

replace CSF36_29happy= 6 if CSF36_29happy== 1
replace CSF36_29happy= 5 if CSF36_29happy== 2
replace CSF36_29happy= 4 if CSF36_29happy== 3
replace CSF36_29happy= 3 if CSF36_29happy== 4
replace CSF36_29happy= 2 if CSF36_29happy== 5
replace CSF36_29happy= 1 if CSF36_29happy== 6

gen menthealth_total = CSF36_23nervous+ CSF36_24down+
CSF36_27downhearted+ CSF36_25calm + CSF36_29happy

* Reported health Transition

replace CSF36_2Ghealth1=. if CSF36_2Ghealth1!= 1 &
CSF36_2Ghealth1!= 2 & CSF36_2Ghealth1!= 3 & CSF36_2Ghealth1!= 4 &
CSF36_2Ghealth1!= 5

* transformation of scale scores

**physical functioning
gen PF = ((physicalfnc_total- 10)/20)*100

**Role_physical
gen RP = ((rolephysc_total - 4)/4)*100

**Bodily Pain
gen BP = ((bodily_total - 2)/10)*100

**General Health
gen GH = ((genhealth- 5)/ 20)*100

**Vitality
gen VT = ((vitality_total - 4)/20)*100

**Social functioning
gen SF = ((socfunct_total - 2)/8)*100

```

**\*\*Role emotional**

```
gen RE = ((rolemo_total - 3)/3)*100
```

**\*\*mental health**

```
gen MH = ((menthealth_total - 5)/25)*100
```

**\*Mental and Physical Composite Scales**

```
gen pf_z=(PF-82.96845)/23.83795
```

```
gen rp_z=(RP-77.93107)/35.34865
```

```
gen bp_z=(BP-70.22865)/23.35310
```

```
gen gh_z=(GH-70.10060)/21.35900
```

```
gen vt_z=(VT-56.99917)/21.12677
```

```
gen sf_z=(SF-83.56494)/23.02758
```

```
gen re_z=(RE-83.10276)/31.64149
```

```
gen mh_z=(MH-75.21913)/17.60698
```

```
gen
```

```
agg_phys=(pf_z*.42402)+(rp_z*.35119)+(bp_z*.31754)+(gh_z*.24954)+(vt_z*.02877)+(sf_z*(0-.00753))+(re_z*(0-.19206))+(mh_z*(0-.22069))
```

```
gen agg_ment=(pf_z*-.22999)+(rp_z*-.12329)+(bp_z*-.09731)+(gh_z*-.01571)+(vt_z*.23534)+(sf_z*.26876)+(re_z*.43407)+(mh_z*.48581)
```

```
gen PCS=(agg_phys*10)+50
```

```
gen MCS=(agg_ment*10)+50
```



**Mental and physical illness in caregivers: results from an English national survey sample 2007**

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**Tables x 4, Figures x 1**

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## **ABSTRACT**

### **Background**

Caregivers make a significant and growing contribution to the social and medical care of people with longstanding disorders. The effective provision of this care is dependent on their own continuing health.

### **Aim**

To investigate the relationship between weekly time spent caregiving and psychiatric and physical morbidity in a representative sample of the population of England.

### **Method**

Primary outcome measures were obtained from the Adult Psychiatric Morbidity Survey 2007. Self-report measures of mental and physical health were used, along with total symptom scores for common mental disorder derived from the Clinical Interview Schedule-Revised.

### **Results**

25% (N=1883) of the sample identified themselves as caregivers. They had poorer mental health, and higher psychiatric symptom scores than non-caregivers. A significant dose effect was found, with an observable decline in mental health above 10 hours per week. A twofold increase in psychiatric symptom scores in the clinical range was recorded in those providing care for more than 20 hours per week. In adjusted analyses, there was no excess of physical disorders in caregivers.

### **Conclusion**

We found strong evidence that caregiving affects the mental health of caregivers. Distress frequently reaches clinical thresholds, particularly in those providing most care. Strategies for maintaining the mental health of caregivers need to consider this adverse and progressive impact, particularly as demographic changes are set to increase involvement in caregiving roles.

### **Declaration of Interest**

None

## **INTRODUCTION**

Large numbers of people provide help and support to friends or relatives unable to manage as a result of old age or ill health [1]. The latest figures from the 2011 Census record that one person in ten in England and Wales recognizes themselves as a caregiver [2]. The financial and social significance of these caregivers (also commonly referred to as unpaid or informal carers) is substantial, and growing [3]. Over the last 10 years, the increase in caregiving has exceeded population growth in Britain, particularly for those providing greater amounts of care (over 20 hours per week) [2]. In the context of a community care approach and a prolonged recession, governments in many jurisdictions have prioritised development of policies directed at caregivers as they attempt to respond to the needs of rapidly aging populations [4].

In the UK a Carers Strategy recommends the early identification of individuals with caregiving responsibilities so that, both for their own benefit and that of the people they care for, they can be supported to maintain their physical and mental health [5]. General Practitioners have been targeted as a critical first point of contact in encouraging individuals to identify themselves as caregivers, while ‘quick tools’ are in development to assess levels of care provision and its impact on individuals [6,7]. Appropriately controlled studies have generally shown that caregivers experience worse health than non-caregivers [8]. Meta-analyses also report consistent associations between caregiving and poor mental health outcomes [9]. However, effect sizes for physical health have been smaller, and fluctuate between impaired and improved physical health in caregivers relative to non-caregivers [10]. Recent research has therefore focused on identifying predictors of the magnitude of the health impact of caregiving [11-16].

We examined the relationship between the number of hours spent caregiving per week and physical and mental health, based in an English national sample (the 2007 Adult Psychiatric Morbidity Survey: APMS 2007 [17]). We hypothesised that those reporting higher amounts of caregiving would not only perceive their mental health as poorer than non-caregivers but would also report increased psychiatric symptomatology as assessed by a standardised clinical interview.

## METHOD

### *Sampling procedure*

The APMS 2007 survey employed a stratified, random probability sampling method to provide robust weighted data representative of the English adult population aged 16 and over. Interviews were conducted between October 2006 and December 2007. Private households were identified via the small user Postcode Address File (PAF). The small user PAF consists of all Royal Mail delivery points receiving fewer than 50 items of mail each day. It provides a comprehensive database of private households in England. The proportion of households living at addresses not on the PAF is estimated at less than 1%. The primary sampling units were individual or grouped postcode sectors, which were stratified by regional area and markers of socio-economic status. Delivery points were randomly selected within each postcode sector, based on probabilities calculated in proportion to size (the number of delivery points). Site visits yielded 13171 eligible addresses for inclusion, and one person over the age of 16 was selected from each identified household using the Kish grid method [18]. A total of 7,304 people (57% of those potentially eligible, and 70% of those successfully contacted) completed interviews with trained representatives from NatCen Social Research. Information was collected on socio-demographic characteristics, general health, psychiatric symptoms and service use. Ethical approval for APMS 2007 was granted by the National Research Ethics Service.

### *Identifying caregivers*

Caregiving responsibilities were assessed by computer-assisted face-to-face interview. Individuals were asked whether or not they *'look after, or give help or support to family members, friends, neighbours or others because they have a long term physical or mental ill-health or disability, or problems related to age?'* This definition is consistent with comparative surveys (Survey of Carers in Households 2009/2010, National Census 2011, General Households Survey 2000) in avoiding use of the term 'carer' and in specifying long term, as opposed to temporary, illness. Participants were also asked to exclude anything which constituted paid employment. Respondents estimated hours spent caregiving per week (hpw) on a 9 point categorical scale (hours per week: 0-4, 5-9, 10-19, 20-34, 35-49, 50-90, >100, <10 but varies, >10 but varies). The inclusion of zero hours per week in the scale enabled individuals self-identifying as caregivers and engaged in a few hours of

caregiving activity regularly on a monthly basis to be differentiated from non-caregivers. Travel time associated with caregiving tasks was included within these estimates.

#### ***Clinical Interview Schedule – Revised (CIS-R)***

The CIS-R is a standardised clinical interview developed for administration by lay interviewers [19]. It assesses psychiatric symptoms relating to specific diagnostic areas, such as depressive and somatic symptoms, generalised anxiety and social phobia. Filter questions establish the presence or absence of particular reference symptoms within the last month. Further questions assess frequency, severity and duration, and time since onset, and the instrument can be used to provide a total symptom score of 0-57, an objective measure of affective disturbance, broadly defined. The accepted clinical threshold for psychiatric morbidity is  $\geq 12$  [20]. To assess clinical significance, a fourfold categorisation, in addition to overall score, was used for analyses in the present study (0-6, 7-11, 12-17, 18+). Analyses relating to individual ICD-10 diagnoses will be examined elsewhere [21].

#### ***Medical Outcomes Study Short Form Health Survey (SF-12)***

The SF-12 is a self-report questionnaire assessing perceived general health and wellbeing. It represents a subset of items from the SF-36. The original scale has demonstrated reliability, validity and sensitivity in discriminating changes across patient groups [22, 23]. Correlations between the SF-12 and SF-36 have been reported at  $r>0.94$  and the shortened scale has been cross-validated across countries and age groups [24, 25]. Items in the SF-12 form 8 health domains that are in turn used to calculate aggregate scores for physical and mental health, with higher scores indicating perceptions of better health [26, 27]. Norm-based scoring was employed, using US population norms, which have demonstrated applicability to UK populations [28, 29]

#### ***Chronic physical conditions***

Individuals endorsed the presence or absence of a series of 21 chronic physical conditions in the preceding year. The APMS uses a show card to ensure comprehensive coverage of physical conditions that people may not otherwise think to mention (e.g. problems with skin or hearing). The list comprised cancer, diabetes, epilepsy, migraine, cataracts/eyesight problems, hearing difficulties, stroke, heart attack, high blood pressure, bronchitis, asthma, allergy, ulcers, liver problems,

bowel/colon problems, bladder problems, arthritis, bone, back or joint problems, infectious disease and skin problems. The card additionally includes a clause stipulating that the condition must have been present in adulthood and diagnosed by a health professional.

### ***Statistical Analysis***

The “Survey” commands in STATA 10 for Windows were used as they provide robust estimates of variance in complex data-sets. Weights were calculated to provide a representative national sample, taking into account survey design and non-response. For more information on the weighting system, see the main APMS report [30]. In the present study, actual counts are presented, together with weighted means and proportions and 95% confidence intervals as estimates of variance. To reduce standard error, the categories denoting hours spent caregiving per week (hpw) were combined to form five groups for descriptive and inferential statistical analyses (0-9, 10-19, 20-24, 35-99, >100hpw). This was further reduced to three groups (non-caregivers, 0-19hpw and  $\geq 20$  hpw) when comparing proportions of people meeting clinical thresholds for psychiatric symptoms, due to low numbers at higher symptom levels. Group differences were assessed with uncorrected Chi-squared and design-based ANOVA tests. Multiple regression analyses were conducted to examine the relationship between caregiving hours and health outcomes, taking into account putative confounding factors, identified from the existing literature and confirmed by correlation analyses (age, sex, employment status, marital status, social support, smoking status, daily alcohol consumption, and body mass index). Unstandardised co-efficients are quoted.

## **RESULTS**

### ***Frequency of caregiving***

Twenty five percent (n=1,883) of participants identified themselves as regular caregivers, of whom nearly all (n=1,874) gave an indication of the number of hours per week (hpw) engaged in caregiving activities. Participants who did not quantify time spent caregiving (n=9) and those who indicated that their hours varied (>10 hrs) on a weekly basis (n=46) were excluded from analyses.

### **Table 1**

Women were significantly more likely than men to identify themselves as caregivers ( $\chi^2 = 10.3$ ,  $df = 1$ ,  $p < .01$ ) and to be engaged in higher levels of caregiving activities ( $\chi^2 = 28.7$ ,  $df = 5$ ,  $p < .0005$ ). In addition, caregivers were more likely to be married ( $\chi^2 = 31.9$ ,  $df = 1$ ,  $p < .0001$ ) and to be unemployed or not to have worked in the last year ( $\chi^2 = 9.9$ ,  $df = 3$ ,  $p < .05$ ). In total 4.4% of the sample reported providing care for more than 20 hours per week. The mean age in this group was significantly higher than for those providing less care (0-19hpw) and for non-caregivers ( $F(5, 256) = 14.0$ ,  $p < .0001$ ).

### ***Measures of mental and physical health***

Perceived mental health (SF-12 mental component summary, MCS) was significantly correlated with total scores on the Clinical Interview Schedule-Revised (CIS-R) ( $r = -.54$ ,  $p < .0001$ ). Likewise, perceived physical health (SF-12 physical component summary scores, PCS) was significantly correlated with the number of diagnosed physical conditions reported by individuals in the preceding year ( $r = -.47$ ,  $p < .0001$ ).

### ***Mental Health***

Even after adjustment for relevant confounding factors in multivariate regression (physical health summary score, age, sex, employment status, marital status, social support, daily alcohol consumption, and body mass index), caregivers had significantly higher total scores on the CIS-R than non-caregivers (Table 2). A dose effect was observable for the amount of caregiving. When the proportions of people reaching clinical thresholds for psychiatric symptoms were compared (Table 3), participants engaged in greater amounts of caregiving ( $\geq 20$ hpw) were twice as likely as non-caregivers to report CIS-R scores of 12 or more.

### **Table 2**

### **Table 3**

Results for perceived mental health (SF-12 MCS scores) were consistent with CIS-R derived measures of psychiatric morbidity (Table 4). Examination of unweighted mean scores on the CIS-R and SF-12 indicated a progressive rate of decline in mental health beyond 10 hours per week of caregiving (Figure 1). On both measures there is a suggestion that people in the second highest

category of amount of caregiving (35-99 hpw) have better mental health than those in the category immediately below (25-34 hpw).

#### **Table 4**

#### **Figure 1**

#### ***Physical Health***

Caregivers reported experiencing a higher mean number of physical illnesses in the preceding year than non-caregivers (non-caregivers: mean = 0.86, 95% CI [0.82, 0.90]; 0-19hpw caregiving: mean = 0.98, 95% CI [0.92, 1.04],  $p < .005$ ;  $\geq 20$ hpw caregiving: mean = 1.16, 95% CI [1.02, 1.30],  $p < .0001$ ). However, while group differences were significant when tested in unadjusted regression analyses, they ceased to be so after controlling for potential confounding factors.

Unadjusted regression analyses of the relationship between hours spent caregiving and standardised SF-12 physical component summary scores (PCS) were also carried out. In comparison to non-caregivers, people engaged in higher amounts of caregiving ( $\geq 20$ hpw) reported significantly poorer perceived physical health ( $B = -1.26$ , 95% CI [-2.42, -0.11],  $p = .03$ ). This association was non-significant for lower amounts of caregiving (0-19 hpw,  $p > .05$ ). Following the introduction of putative confounding factors in the regression (mental health summary scores, sex, age, marital status, employment status, daily alcohol consumption, body mass index (BMI), and social support), higher amounts of caregiving were actually associated with better physical health summary scores, albeit not significantly so (0-19 hpw:  $B = 0.31$ , 95% CI [-0.25, 0.87],  $p > .05$  and  $\geq 20$ hpw:  $B = 0.96$ , 95% CI [-0.19, 2.11],  $p > .05$ ). Participants' age, employment status and body mass index contributed most to the variance in PCS scores.

## **DISCUSSION**

### ***The frequency of caregiving***

One in four people aged over 16 in households identified themselves as a caregiver during the APMS 2007 interviews. This is twice the rate reported by the Survey of Carers in Households (SCH), 2009/2010 (10.9%) and by the UK Census 2001 (12.3%). This discrepancy might relate to the survey questions, to context, or to the sampling design. The SCH 2009/2010 notes for example the potential for its methodological approach to underestimate 'lighter touch' or lower intensity



caregiving [31]. Frequencies obtained by interviews conducted with a respondent ‘nominated by the householder’ (as was the case for the SCH) are likely to differ from those where all members of the household are interviewed [32]. Both the General Household Survey (2000/2001) and the British Household Panel Survey (2007) used the latter approach, and obtained somewhat higher estimates for the caregiving population, at 16.1% and 17.0% respectively. In the APMS, one member was selected at random from each household and weighting was used to render the sample representative of the adult population in England. Using this robust approach, it also reports a larger caregiving population. The excess in the frequency of caregivers is restricted to those engaged in fewer caregiving hours per week (0-19hpw). Rates of individuals engaged in higher amounts of caregiving ( $\geq 20$  hpw) are relatively consistent (APMS 2007: 4.4%, SCH 2009/2010: 5.2%; Census 2001: 3.9%, GHS 2000: 4.1%). Contrary to the Census which identifies individuals taking part in at least 1 hour per week (hpw) caregiving, the APMS includes 0hpw in its first category. This allowed for people providing regular caregiving of less than 4 hours over a monthly period, and may account for the higher frequency of people taking part in lower amounts of caregiving. Alternatively, political and media attention may have influenced public acknowledgment of everyday activities as constituting ‘caregiving’. However, this might be expected to affect all surveys equally. If, nevertheless, the difference indicates early-stage caregiving in relation to an ageing population, it should be noted. Corresponding increases in higher amounts of caregiving might in consequence be expected in the future. Indeed although age-standardised rates of caregiving from the 2011 Census (completed after the APMS 2007) are yet to be released, provisional analyses suggest that the greatest rate of growth in the caregiving population over the last 10 years has been observed in those providing more than 20 hours per week of care. At least for higher levels of care, most caregiving relationships in the APMS 2007 involved the provision of care by older participants. This is reflected in the predictive influence of age in the multivariate regression of physical health outcomes.

### ***The impact of caregiving***

As predicted, caregiving was significantly associated with poorer mental health outcomes. This relationship remained robust in regression analyses even after the inclusion of confounding factors. The causal direction is unclear. Increased psychiatric symptomatology and rates of common mental disorder in caregivers may reflect shared vulnerabilities which have led biologically and

socially related care-recipients to require support themselves. However, a number of considerations may suggest that the mental health correlates are responses to the caregiving role. First, a relatively objective measure of amount of caregiving (number of hours per week) was used, as opposed to scaled measures of subjective feelings of burden [12] which are likely to have a higher correlation with psychological distress [10]. Second, a significant and sizeable dose effect in relation to amount of time devoted to caregiving per week was observed, with more pronounced declines in mental health observed at upwards of 10 hpw and also at greater than 100 hpw spent caregiving. This is consistent with studies analyzing trajectories of caregiving in earlier national samples [33,34], and is difficult to interpret in terms of self-selection of psychiatrically disadvantaged people into the caring role. Third, again in line with previous studies, the relationship reported between caregiving and physical health was inconsistent, being significantly affected by moderating factors. The caregivers in question are older than the national average, and older populations generally have worse physical but better mental health than the average [35,36]. The fact that this pattern was so different in caregivers is difficult to explain in terms of selection, and therefore makes a direct effect of the caregiving role on mental health a more likely explanation.

Caution is nevertheless advisable in interpreting the clinical significance of the dose-response relationship between hours per week spent caregiving and severity of psychiatric symptoms. A limitation associated with categorising caregivers according to hours spent caregiving is that it may implicitly suggest a uniform impact of care associated with one unit hour. Caring for people with mental as well as physical health problems is known to be associated with higher levels of distress than caring for those with physical health issues alone [37]. This distress may accordingly be experienced at lower amounts of caregiving, which further justifies the inclusion of individuals who identify as carers but who quantify their regular level of caregiving activity at less than 1 hour per week (0hpw). The observed dose-response relationship may therefore be moderated by variables such as care-recipient illness, kinship and face-to-face contact time. It may also be affected by changes in available resources and competing demands. A partial reversal in declining CIS-R scores associated with increased caregiving hours was observed at the second highest amount of caregiving (35-99 hpw). This might be explained by changes in compounding stressors including employment as people retire and take on greater caregiving activities associated with older age. A substantial increase in the

proportion of people not having worked in the last year was observed in those endorsing 35-99hpw caregiving by comparison to lower amounts of care (Table 1). It may alternatively indicate some psychological adjustment to the stresses associated with caregiving as hypothesised in stress-appraisal-coping models [38].

We anticipated that greater data capture in the 0-19hpw caregiving group by comparison to previous surveys might accentuate reported differences in outcome measures when compared with individuals engaged in higher amounts of caregiving ( $\geq 20$ hpw). This provided one rationale for ensuring that comparisons in outcome measures were made across at least 3 groups of caregivers (including non-caregivers). However, a dose-response relationship was consistently observed between amount of caregiving and health outcomes in comparisons based on a three-group split and a five-group split. Nevertheless, within-group variation in the levels of distress experienced per unit hour of caregiving activity should not be underestimated.

### ***Limitations***

The data relied on self report, without collateral corroboration. This might lead to under-reporting of physical conditions: participants may have undiagnosed symptoms, or they may be unaware or forgetful of a previous diagnosis. The requirement that physical conditions had been diagnosed by a health professional however should increase consistency by constraining the ailments included. The validity of findings from self-report measures is also supported by the significant correlations between perceived and observer-rated measures of physical and mental health. Furthermore, self-reported mental health has intrinsic value as an indicator of psychological distress, particularly given the central role of subjective carer appraisals in cognitive models of carer burden or impact of care [38, 39]. The study also relied on self-report for measuring time spent caregiving. Whilst this method has been validated, it may lead to overestimations or underestimations of caregiving levels and is less accurate than diary techniques [40]. In addition, the APMS survey did not assess some important characteristics of caregiving roles, which we were therefore unable to analyse in relation to physical and mental health. These included the basis of the relationship between caregiver and care-recipient, whether they lived together, the duration of the caregiving role, and the type of illness suffered by care-recipients. Our findings therefore relate to the generality of caregiving: caring for

people with specific problems may result in specific patterns of impact. Finally the data were obtained cross-sectionally, which limits causal inference.

### ***Implications***

We have demonstrated the significant health consequences of caregiving, even at lower levels of care. This is relevant to approximately 5.8 million people in England and Wales who currently identify themselves as caregivers [2]. For individuals providing more than 20 hours per week of care (over 2 million in England according the 2011 Census), the mean excess score in comparison to non-caregivers was three points on the CIS-R. In contrast, the equivalent change in CIS-R score in relation to the unpleasant experience of job loss was zero in two thirds of participants, and around one for most of the remainder [41]. Moreover, the proportion of individuals meeting clinical thresholds for psychiatric symptoms in this group was twice that observed in non-caregivers.

Our results indicate, first, the need for pre-emptive policies to identify caregivers at an early stage and to target support services appropriately. This raises the issue of how best to identify and communicate with caregivers at an early stage. Second, whilst varying definitions of caregiving might lead to variations in reported frequency, the present study affirms that objective measures of caregiving demand (hpw) are informative. Hence, we recommend their inclusion in the quick assessment instruments being developed for caregivers [6,7]. Finally, understanding differences in the impact of caregiving roles in relation to individuals with different mental and physical conditions will help services to provide targeted information and support for enabling families to cope effectively.

While these considerations will apply across jurisdictions, recent developments in the UK are of interest. The government is embarking on an ambitious new public health strategy that stipulates *'No health without mental health'* and which centres on the devolution of public health governance to local communities [42, 43]. *'Carers at the heart of 21<sup>st</sup>-century families and communities'* is the title of the current UK Carers Strategy [44]. The Department of Health has funded a *'Supporting Carers in GPs programme'* and, in association with the Royal College of General Practitioners (RCGP), has conducted a pilot training programme (2010) for GPs on best practice in incorporating a carers' policy [45, 46]. Carers UK continues to train volunteer Carer Ambassadors to act as liaison

officers in directing this policy in practice [47]. However, despite positive feedback on the pilot, it was noted by participants that *'services for carers were unlikely to improve significantly without incentives and additional resource.'* [45]. GPs are already taking on increased duties in administering the Clinical Commissioning Groups proposed by the Health and Social Care Bill. In addition, evidence suggests that taking on a caregiving role does not necessarily translate into increased contact with primary care service [48]. The development of tangible actions to identify and engage caregivers remains a priority.

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## **DECLARATIONS**

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All authors have completed the Unified Competing Interest form at [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) (available on request from the corresponding author) and declare that (1) they have no support from any organisation for the submitted work; (2) they have no relationships with any organisations that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) they have no non-financial interests that may be relevant to the submitted work.

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